[4077]

Seattle-King County

**AIDS Prevention and Services**

# Five Year Plan

Spring 1989

Department of Public Health

# Preface

This Five Year Plan for AIDS Prevention and Services in Seattle-King County was developed for these purposes:

- to present a picture of where the AIDS epidemic is headed in Seattle-King County over the next five years (that is, through 1993);
- to outline the prevention activities and health care and social support services which should be in place to respond to the epidemic and where gaps in or problems with availability or access in these will occur; and
- to identify the magnitude of resources required to support the needed programs and services.

The Plan is not a funding allocation document but should be used to guide allocation decisions by identifying needed programs and services. In this way it should be useful to funders, both public and private, in pointing out areas where their funds could have the greatest effect, and to providers in identifying priority areas for development of prevention programs and services.

The Plan was prepared during 1988 and 1989 and is the first long-range plan for AIDS prevention and services for Seattle-King County. While it contains a wealth of information and is the result of a substantial planning effort on the part of nearly 150 individuals from throughout the community, the Plan is not *finished,* nor should it ever be. Any plan should contain provision for regular updates and expansion and especially in the rapidly evolving area of AIDS, this is essential. The Seattle-King County Department of Public Health is committed to assuring that such a process is in place and operative.

Development of the Five Year Plan was authorized by Dr. Bud Nicola, Director of the Seattle-King County Department of Public Health. He was assisted by a broad-based Steering Committee: Patricia McInturff, Dr. Bob Wood, Judith Pierce, Jack Thompson, Phil Showstead and Bruce Miyahara from Seattle-King County Department of Public Health; Catlin Fullwood from People of Color against AIDS Network; Bea Kelleigh and Barry Bianchi from the Northwest AIDS Foundation; Dr. Ann Collier from Harborview Medical Center; and Gary Lawrence from the Suburban Cities. For each of the major sections of the Plan, workgroups from the community were constituted to help in identifying issues, program gaps and the like. To the extent possible, existing groups which were involved in the areas under discussion formed the basic workgroups with invitations to others in the community to participate. In May 1989, a public hearing was held on the Plan and comments made were incorporated in the document.

With development of this Plan, Seattle-King County joins only a handful of other locations around the country where long-range planning for the AIDS epidemic has taken place, and this community once again affirms its intent to deal with this challenge in an active rather than a reactive fashion.

SEATTLE-KING COUNTY

AIDS PREVENTION AND SERVICES

FIVE YEAR PLAN

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# I. Demographics

## Introduction

King County's estimated present and projected population figures are as follows:

| | |
|---|---|
| 1987–88 | 1,384,600 [1] |
| 1988–89 | 1,404,100 |
| 1989–90 | 1,423,500 |
| 1990–91 | 1,453,500 [2] |

Although only eleventh largest in land area – 2,130 square miles – King County is by far the most populous of Washington's 39 counties. Its population is more than twice the size of its neighbor to the south, Pierce County, the next largest. King County has 31% of the total State population of 4.5 million, and holds 8 of the 25 largest cities in the state: Seattle, Bellevue, Renton, Auburn, Redmond, Kent, Mercer Island, and Kirkland.

Since 1980, King County has gained one-third of the state's population growth and new housing units. King County's net immigration of nearly 51,000 people represents more than one-half of the state's net migration from 1980–87.

Seattle, being the most populous city in King County, had a 1987 estimated population of 491,300 or 36% of the total County population. In terms of population density, Seattle approximates 1,500 people per square mile, compared to the rest of King County's 605. However, from 1980–87, Seattle's population growth has decreased by 0.5% while King County, outside of Seattle, has increased by 9.0% – a trend which is expected to continue through the year 2000.

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1 1987 Population Trends for Washington State, Washington State Office of Financial Management

2 Rough projections based on consistent 2.4% growth.

# Past and Current Dimensions of the AIDS Epidemic

## A. Reported Cases of AIDS

**The material in this Chapter was prepared in the summer of 1988 for submission to the State Office of HIV/AIDS and would require extensive rewriting to render it completely up–to–date. Since the overall trends and future projections have not changed, we decided to wait to undertake this task until a second edition of the plan is prepared, perhaps in early 1990. It is important to report that as of May 16, 1989, 954 residents of King County had been reported with AIDS, and 446 of these survive.[1]**

Through July 31, 1988, 685 residents of King County have been reported to have AIDS[1]. This is 75% of the total diagnosed in Washington State (see Table 1). 410 of those diagnosed resided in the Central District, Capitol Hill, Denny Regrade and Queen Anne areas of Seattle. 97 came from the area north of the Ship Canal to the County line and bounded by Lake Washington to the east. The remaining 168 were from other east and south areas in the County (see Table 2).

The cases to date have been overwhelmingly white (92%), homosexual/bisexual men (94%, including 9% who are also IV drug users), ages 20 to 49 (90%). (see Table 3).

The proportion of people of color who have been diagnosed with AIDS in King County and the proportion of total area population are as follows.

| | Number Diagnosed with AIDS | As of 7/31/88 Percent of Total Diagnosed with AIDS | Percent of Total Population |
|---|---|---|---|
| Black | 36 | 5.3% | 4.6% |
| Hispanic | 13 | 1.9% | 2.7% |
| Other/Unknown (includes American Indian and Asian) | 10 | 1.5% | 1.0% American Indian<br>5.7% Asian<br>0.9% Other |

See Table 4 for trends in AIDS cases by race.

Anecdotal information, both locally and nationally, suggests that American Indians are underreported among those diagnosed with AIDS. Other minority groups including Asians and Pacific Islanders may also be underreported.

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1 This is the number reported to the Centers for Disease Control according to their definition of AIDS. In Washington State more types of cases such as wasting syndrome and HIV-related dementia are reportable. See Appendix A for classification system and differences between CDC and Washington State reporting requirements. In this plan all past and current numbers and characteristics of persons with AIDS are derived from CDC reporting. All projections use Washington State reporting requirements for assumptions. This increases by approximately 40% what is reported to the CDC.

With respect to ages of those diagnosed, the 20% of total cases who are between the ages of 20 and 29 are of particular concern because many were likely infected as adolescents, given the lengthy incubation period of the virus, now estimated to be 10–14 years.

Regarding children, although there are a number of seropositive infants and children in King County (see next section ), only 4 infants with AIDS have been diagnosed in the County since the beginning of the epidemic. There is general agreement that the problem is somewhat greater than reflected in the small number of children diagnosed with full blown AIDS. This is due to the types of reporting required for infants, some suspected underreporting, and missed diagnoses.

With respect to hemophiliacs, in King County 12 have become sick and 4 have already died.

With respect to survival time from diagnosis to death, analysis of Persons with AIDS in Washington State from 1983 to 1988 showed that the mean overall survival time after diagnosis was 13.5 months. By presenting diagnosis, the mean survival was 19.7 months for persons with Kaposis Sarcoma (KS), 14 months for those with Pneumocystis carinii pneumonia (PCP) and 9.8 months for all other diagnoses. One–fourth of cases with PCP survived 22 months after diagnosis while one–fourth of cases with KS survived 41 months after diagnosis. Mean overall survival times increased by more than 50% between 1983 and 1986.

As may be seen in Table 3, almost two–thirds of the PWAs in King County were diagnosed with PCP while just over one in ten were diagnosed with KS alone.

It should be noted that a sizable proportion (perhaps half) of PWAs have neurological involvement along with other problems. While this can be profound, it often occurs near the end of their illness when many other bodily dysfunctions are also occuring. There are few cases where neurological problems are the only debilitating functions, although mild neuropsychological involvement is common.

## B. Seroprevalence Estimates and Related Information

"Seroprevalence" refers to the rate of HIV infection in a group or population as a whole.

Reliable data regarding seroprevalence are not available. In King County, the "best guesstimate" is that there are probably 20 persons infected with the HIV virus for every I with full blown AIDS. It is antici–pated that this ratio will decrease over time as more of the infected persons develop AIDS and as education and prevention programs are successful in preventing further spread of infection. As the pool of infected become sick and die and if few new persons are added, the pool will decrease in size — especially relative to the number of persons sick. For planning purposes, it is estimated that the ratio of infected persons to PWAs will be l0 to I by l993.

It is important to note that, just as AIDS is unevenly distributed in the population, so is seropositivity. Furthermore, the infected populations have received differing amounts of education regarding prevention of HIV infection and have responded to the information they have received with varying levels of behavior change. For example, gay men have made major changes, IV drug users have made some, and heterosexuals have made little or no change.

The sizes of the populations at risk for HIV infection can only be estimated.

Gay males may comprise 15% of the male population of King County, or 100,000 of the 700,000 males in KC. Kinsey data from the 40s suggest 10% of adult males are gay, but recent studies in San Francisco suggest 25% there are primarily homosexual. Seattle is very similar to San Francisco, so it may have a higher gay prevalence than the United States in general. Of this population, however, only perhaps half (50,000) are sexually active enough to be at risk.

Intravenous Drug Users are estimated by multiplying the number of different individuals enrolled in treatment programs (2,000 in 1986) by 6, yielding 12,000 IVDUs. This reflects the "rule of thumb" that, for everyone in treatment, there are approximately five more users. Some of these 12,000, of course, are women. In addition, there is some number of female partners of male IVDUs, though they are at less risk for contracting HIV infection, being farther removed from source of the infection.

There are 400 hemophiliacs in Washington State. Since one–third of the State's population is in King County, there are approximately 133 living in King County.

Regarding the rate of infection in these groups, the data are biased by the factors that lead people to be tested. Persons at higher risk are more likely to report to testing sites, those with symptoms the same, etc. Thus, estimates may be inflated by looking soley at data from voluntary testing sites. In any case, here are the best available estimates in Seattle–King County with a projection of how many individuals are infected.

| | | |
|---|---|---|
| Gay Males | 40% | infected among those seen at Harborview Sexually Transmitted Diseases Clinic |
| | 27% | infected among the AIDS Prevention Project's **Be A Star** study participants<br>Estimated Number Infected: 13,000 (27% X 50,000) |
| IVDUs | 33% | among those men who also indicate they have male–male sex when seen at the AIDS Project or King County Correctional Facility |
| | 7% | among those who deny having male–male sex when interviewed at the AIDS Project or King County Correctional Facility<br>Estimated Number Infected: 840 (7% X 12,000) |
| Hemophiliacs | 22.5% | of hemophiliacs locally are infected (using Washington State infection rate)<br>Estimated Number Infected: 30 (22.5 X 133) |
| General Population | .02% | among first–time blood donors locally |
| | .07% | among military recruits |

Sweden Conference reports suggest true general population prevalence is about 4 times what military recruit data show, thus maybe .3% of the general population infected.
Estimated Number Infected: 4200 (.3% X 1.4M)

| | |
|---|---|
| People of Color | of persons tested at the AIDS Prevention Project from June 1986 to June 1988, the following are results by sex and race. |

There are several important reasons to have some information about the rate of seropositivity and size of the at–risk population. First, many of those infected will eventually develop debilitating illnesses related to HIV infection or will develop full blown AIDS. Second, if it is known where the higher rates are, prevention programs can better be targeted to these populations, and to the behaviors which put them at risk and, consequently, program impact could be measured. To elaborate, since primary prevention aims to change behaviors that place persons at risk of HIV infection (unprotected sex or needle sharing with infected persons), the larger the size of the population that engages in such behaviors, the larger the primary prevention program needs to be (behavioral prevalence). This is more important than the rate of seroprevalence in these populations. For example, with only 7% seroprevalence among IVDUs, one could argue that not many prevention resources need be spent; however, clearly, now is the time to invest in those programs, before this population becomes infected.

| | Number Tested | Number Positive | Percent Positive |
|---|---|---|---|
| **Female** | | | |
| White | 813 | 24 | 3% |
| Black | 40 | 3 | 8% |
| Other | | | 0% |
| **Male** | | | |
| White | 2,717 | 599 | 21% |
| Black | 118 | 32 | 27% |
| Hispanic | 82 | 22 | 33% |
| Native American/ Alaska Native | 30 | 11 | 37% |
| Asian | 57 | 17 | 12% |

The relative magnitude of secondary prevention efforts on the other hand, will depend on the size of the infected pool – more care is needed by more HIV infected, more AZT to prevent disease progression, etc.

The proportion of resources to be expended on tertiary prevention activities depends on the mission: a) care of PWAs of course will be proportional to the number of living PWAs; b) parts of the system which require change ought not to be billed against "AIDS" as they were deficits of the current systems (If change occurs, it will be an advantage for the care of all chronically–ill persons); c) the costs of reducing societal fear will probably vary more with the duration of the epidemic, perhaps leveling off as more people become familiar with AIDS and used to dealing with it (however, we have not have yet reached the peak of this fear).

### C. Reported Cases of Hepatitis B

Hepatitis B is merely an available surrogate marker – until we have better data on HIV sero–prevalence. The State has opted to use this since HIV data were not routinely collected. Hepatitis B is a reasonable surrogate in the short term since it is transmitted sexually and via IVDU works, although transmitted more efficiently than HIV.

The rates of Hepatitis B per l00,000 population have been increasing dramatically in the past several years in King County, more than doubling between l985 and l986, although there has been a leveling off in l987 and the first half of l988.

Interestingly, there seem to be consistent Hepatitis B "hotspots" in King County other than Seattle. These include Auburn, Kent and Federal Way. This may warrant additional study to see if IV drug use is excessive in those communities.

## Future Dimensions of the AIDS Epidemic

Tables 5, 6 and 7 contain the projected impact of AIDS and Class IV related diseases for Seattle–King County by the number of cases, by risk category, and for children under 13 years of age (in Washington State).

# Cost and Utilization of Services

## A. What We Know

A study of Washington State's inpatient hospital utilization for 165 AIDS cases with 344 hospitalizations from July 1984 through December 1985 contained these results:

| | |
|---|---|
| Mean inpatient charges | $9,166 |
| Mean length of stay (days) | 3.3 |
| Mean number of hospitalizations | 2.1 |
| Mean follow-up interval (months) | 7.2 |

Although this was a statewide study, 78% of the cases in the study were from King County. This early study, prior to the advent of well developed outpatient services for PWA and regional training programs, suggested that the charges per day were slightly higher outside of King County ($637 vs $877), and a higher proportion were covered by Medicaid outside of King County (49% vs 30%). Later studies suggest that these differences have dissolved over time, perhaps as AIDS training and expertise disseminates from urban to rural areas.

Hospital charges were evaluated from diagnosis to death from July 1984 to July 1987. In general, although the survival time increased, the number of days spent in the hospital decreased. Consequently, the inpatient charges from diagnosis to death decreased from $33,809 to $19,759 from the first 18 months of the study to the last 18 months of the study respectively (see Tables 8 and 9).

Evaluation of the Medicaid data for the first 18 months of the database, suggests annual total charges of approximately $45,000, which include inpatient charges, outpatient charges, physician fees, and other goods and services, such as medications. Although outpatient charges usually range from 5-10% of the total, as outpatient charges for AZT (pharmacy charges $9,000/year) and the expenses associated with its monitoring increase, the ratio of inpatient to outpatient charges may equalize with the total charges remaining the same (i.e., about $45,000/year or less).

The method of payment which predominates the funding of inpatient care of people with AIDS is dependent upon the particular risk group. In areas where IVDU is common, the majority of cases are funded from diagnosis to death by public assistance funds. Areas in which cases gay men predominate, at least 50% of cases will be funded by private methods of payment (see Table 10). Locally, the impact of HIV testing on insurance may eventually be offset by the high risk pool.

Another useful piece of information regarding cost and utilization resulted from a separate analysis of charges for AIDS and non-AIDS hospitalizations within diagnosis-related groups (DRGs). For Code 398 (reticuloendothelial and immunity disorders in those over 70 years or with complications), mean charges were $9,416 for AIDS cases and $4,548 for those without AIDS. For Code 079 (lung inflamation in those over 70 or with complications), mean charges for AIDS hospitalization were $14,830 and for non-AIDS cases, $7,057. The differences reflect significantly longer lengths of stay for persons with AIDS when compared to people with similar conditions who did not have AIDS.

## B. What We Do Not Know

It would be useful if we are to better understand the financial impact of the AIDS epidemic, to know more about outpatient costs, including costs of medications. It would also help to know the magnitude of health resources required by seropositive individuals who do not have full-blown AIDS.

Throughout the remainder of this document, attempts are made to estimate the need for different services by various groups of users. As more experience is gained in providing services, we will be able to predict costs and usage.

## C. Assumptions Regarding Cost and Utilization

For planning, the following assumptions should be used until better information is available.

- Mean survival will move from thirteen months to eighteen months with 25-40% surviving beyond two years.
- Mean number of hospitalizations per year for PWAs will decrease from the current 2.1-3/year to 1.2-1.3/year.
- First year after diagnosis, inpatient days will decrease due to decreased incidence of opportunistic infection and prophylaxis for PCP.
- Second year after diagnosis, most PWAs will experience one lengthy hospital stay as they progress to a point where many body systems are failing.
- Procedures which have to date been done in the first year after diagnosis will be done in the second year.
- Actual cost of care in the second year will be dependent upon the amount of community support available and degree to which home and community-based services are used instead of hospital services.
- AZT and other antiviral medications will be used more broadly for people who are ill with HIV-related illness.

# AIDS Surveillance Report
# 5/16/89

## Cumulative Case Numbers

| | Cases | Deaths | % |
|---|---|---|---|
| Seattle-King County | 954 | 508 | 53% |
| Washington State (5/1/89) | 1,263 | 686 | 54% |
| United States (4/13/89) | 90,990 | 52,435 | 58% |

## Seattle-King County

| 1989 | | 1988 | |
|---|---|---|---|
| 1st Quarter : | 66 | 1st Quarter: | 67 |
| 2nd Quarter, to date*: | 7 | 2nd Quarter: | 78 |
| | | 3rd Quarter: | 79 |
| | | 4th Quarter*: | 60 |

*Reporting for recent months is incomplete

Cases residing in King County at month of diagnosis

Table 2

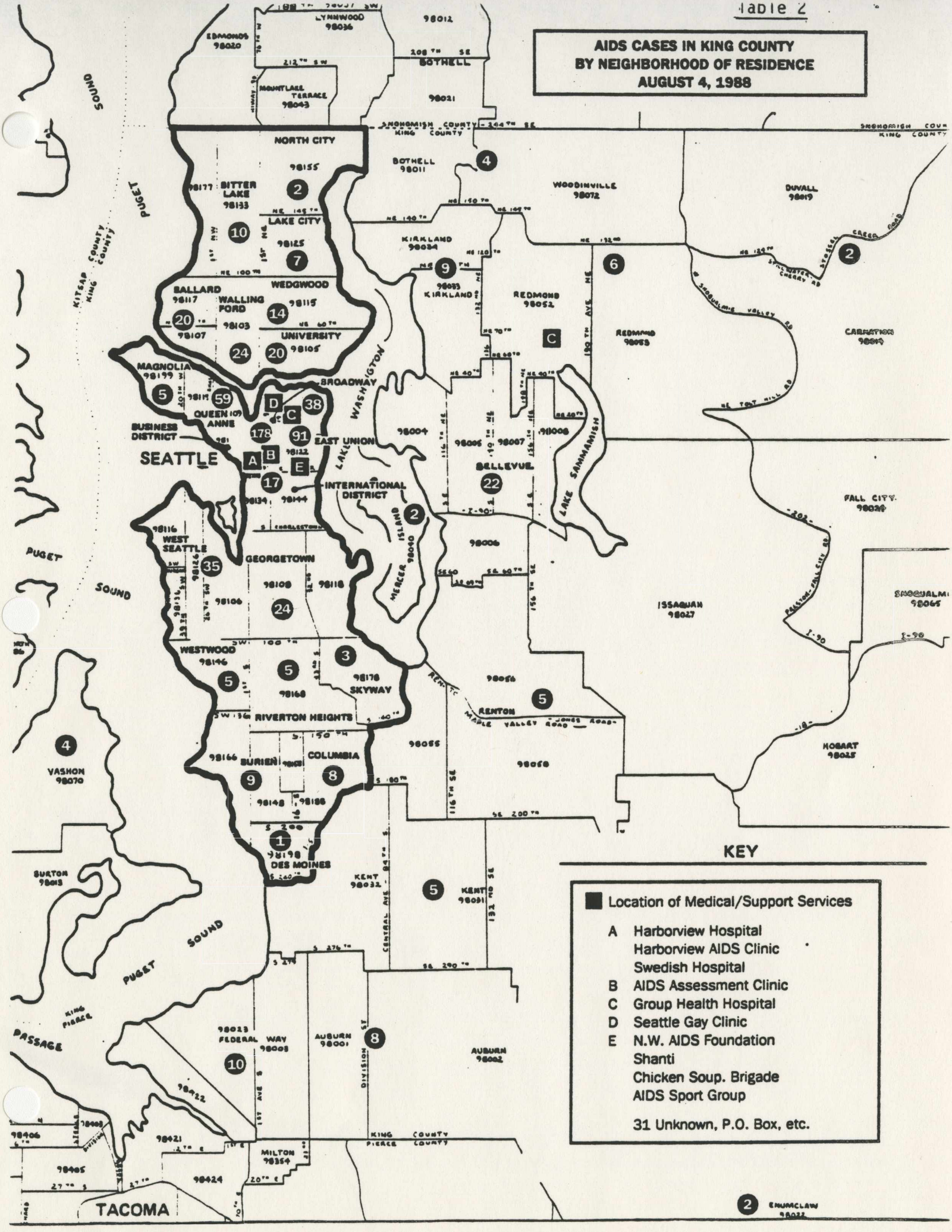

AIDS CASES IN KING COUNTY
BY NEIGHBORHOOD OF RESIDENCE
AUGUST 4, 1988
KEY
Location of Medical/Support Services
A Harborview Hospital
Harborview AIDS Clinic
Swedish Hospital
B AIDS Assessment Clinic
C Group Health Hospital
D Seattle Gay Clinic
E N.W. AIDS Foundation
Shanti
Chicken Soup. Brigade
AIDS Sport Group
31 Unknown, P.O. Box, etc.
SEATTLE
BELLEVUE
TACOMA
PUGET SOUND
LAKE WASHINGTON
LAKE SAMMAMISH
NORTH CITY
BITTER LAKE
LAKE CITY
WEDGWOOD
BALLARD
WALLING FORD
UNIVERSITY
MAGNOLIA
QUEEN ANNE
BUSINESS DISTRICT
BROADWAY
EAST UNION
INTERNATIONAL DISTRICT
WEST SEATTLE
GEORGETOWN
WESTWOOD
SKYWAY
RIVERTON HEIGHTS
BURIEN
COLUMBIA
DES MOINES
VASHON
BOTHELL
WOODINVILLE
KIRKLAND
REDMOND
DUVALL
CARNATION
ISSAQUAH
RENTON
KENT
AUBURN
FEDERAL WAY
MERCER ISLAND
FALL CITY
SNOQUALMIE
HOBART
MAPLE VALLEY
BURTON
MILTON
ENUMCLAW

Table 3

Acquired Immunodeficiency Syndrome (AIDS)
AIDS Reporting System
Surveillance Report for Seattle-King County - 08/01/88

| 1. Disease Category | Adult/Adolescent Cases ( %) | Adult/Adolescent Deaths ( %) | Pediatric Cases ( %) | Pediatric Deaths ( %) | Total Cases ( %) | Total Deaths ( %) |
|---|---|---|---|---|---|---|
| PCP | 431 ( 63) | 233 ( 54) | 1 ( 25) | 1 (100) | 432 ( 63) | 234 ( 54) |
| Other Disease w/o PCP | 177 ( 26) | 101 ( 57) | 3 ( 75) | 0 ( 0) | 180 ( 26) | 101 ( 56) |
| KS Alone | 73 ( 11) | 31 ( 42) | 0 ( 0) | 0 ( .) | 73 ( 11) | 31 ( 42) |
| No Diseases Listed | 0 ( 0) | 0 ( .) | 0 ( 0) | 0 ( .) | 0 ( 0) | 0 ( .) |
| Total | 681 (100) | 365 ( 54) | 4 (100) | 1 ( 25) | 685 (100) | 366 ( 53) |

| 2. Age | Cases ( %) |
|---|---|
| Under 13 | 4 ( 1) |
| 13-19 | 2 ( 0) |
| 20-29 | 134 ( 20) |
| 30-39 | 347 ( 51) |
| 40-49 | 135 ( 20) |
| Over 49 | 63 ( 9) |
| Unknown | 0 ( 0) |
| Total | 685 (100) |

| 3. Race/Ethnicity | Adult/Adolescent Cases ( %) | Pediatric Cases ( %) | Total Cases ( %) |
|---|---|---|---|
| White, Not Hispanic | 624 ( 92) | -- (-- ) | -- (-- ) |
| Black, Not Hispanic | 35 ( 5) | -- (-- ) | -- (-- ) |
| Hispanic | 13 ( 2) | -- (-- ) | -- (-- ) |
| Other | 8 ( 1) | -- (-- ) | -- (-- ) |
| Unknown | 1 ( 0) | -- (-- ) | -- (-- ) |
| Total | 681 (100) | -- ( --) | -- ( --) |

| 4. Patient Groups | Adult/Adolescent Males ( %) | Adult/Adolescent Females ( %) | Adult/Adolescent Total ( %) |
|---|---|---|---|
| Homosexual or bisexual Men | 577 ( 86) | 0 ( 0) | 577 ( 85) |
| Intravenous (IV) drug User | 10 ( 1) | 3 ( 27) | 13 ( 2) |
| Homo/Bi IV drug User | 63 ( 9) | 0 ( 0) | 63 ( 9) |
| Hemophiliac | 5 ( 1) | 1 ( 9) | 6 ( 1) |
| Heterosexual contact | 2 ( 0) | 2 ( 18) | 4 ( 1) |
| Transfusion with blood/products | 6 ( 1) | 3 ( 27) | 9 ( 1) |
| None of the above/Other | 7 ( 1) | 2 ( 18) | 9 ( 1) |
| Total | 670 (100) | 11 (100) | 681 (100) |

| | Pediatric Males ( %) | Pediatric Females ( %) | Pediatric Total ( %) |
|---|---|---|---|
| Hemophiliac | -- (-- ) | -- (-- ) | 0 ( 0) |
| Parent at risk/has AIDS/HIV | -- (-- ) | -- (-- ) | 4 (100) |
| Transfusion with blood/products | -- (-- ) | -- (-- ) | 0 ( 0) |
| None of the above/Other | -- (-- ) | -- (-- ) | 0 ( 0) |
| Total | -- ( --) | -- ( --) | 4 (100) |

Table 4

Trends In King County
AIDS Cases* by Race N=672

| | 1984 and before | | 1985 | | 1986 | | 1987 | | As of 6/30/88 1988 | |
|---|---|---|---|---|---|---|---|---|---|---|
| Black | 3 | (4.8%) | 4 | (4.5%) | 8 | (4.4%) | 10 | (4.3%) | 11 | (10.5%) |
| Hispanic | 1 | (1.6%) | 1 | (1.1%) | 7 | (3.8%) | 3 | (1.3%) | 1 | (.9%) |
| Other | 0 | (0.0%) | 0 | (0.0%) | 3 | (1.6%) | 5 | (2.1%) | 2 | (1.9%) |
| White | 59 | (93.7%) | 84 | (94.4%) | 164 | (90.1%) | 215 | (92.3%) | 91 | (86.7%) |
| TOTAL | 63 | (100.0%) | 89 | (100.0%) | 182 | (100.0%) | 233 | (100.0%) | 105 | (100.0%) |

*For AIDS cases meeting CDC surveillance definition

# Projected Impact of AIDS and Class IV HIV-Related Disease in Seattle-King County 1988 - 1993

| | Projected Cases**** | | | | | |
|---|---|---|---|---|---|---|
| | 1988* | 1989 | 1990 | 1991 | 1992 | 1993 |
| **Cases**** | | | | | | |
| During the year | 469 | 614 | 760 | 943 | 1067 | 1352 |
| Cumulative | 1200 | 1814 | 2574 | 3517 | 4584 | 5936 |
| **Deaths***** | | | | | | |
| During the year | 267 | 350 | 433 | 538 | 608 | 771 |
| Cumulative | 684 | 1034 | 1467 | 2005 | 2613 | 3384 |
| **Total Surviving** | **516** | **780** | **1107** | **1512** | **1971** | **2552** |

## Notes

**These projections represent the most accurate forecasting possible as of mid-1988. Future revisions will undoubtedly be needed as more is learned about the impact of the revised reporting definition, the effect of antivirals and other therapy on survival rates, the rate of progression to Class IV disease in HIV-infected individuals, and local seroprevalence rates. Confidence intervals are not reported here, but are very wide (see reference cited below).**

*1988-1993 projections are under the expanded Washington State surveillance criteria for Class IV HIV-related Disease.

**Projected AIDS incident cases for Washington State calculated by taking 1.3% of U.S. AIDS cases as projected by the CDC (ref: Morgan, AIDS: Current and Future Trends. *Public Health Report* 101:459-65, Sept-Oct 1986) with an additional 40% added for the expanded surveillance criteria. King County cases calculated by taking 78% of State cases of 1987 and 1988, 75% for 1989, 72% for 1990, and 70% through 1993, as per CDC forecasts that the proportion of cases diagnosed in major population centers will decline over time.

***Projected deaths calculated by assuming a 57% cumulative mortality rate. This rate assumes that antiviral chemotherapies will result in prolonged survival times. In the absence of antivirals, a 67% cumulative mortality would have been predicted for 1991.

****Due to incomplete reporting, the actual number of reported cases is expected to be approximately 20% less than the projected impact figures.

*Seattle-King County Department of Public Health*
*AIDS Epidemiology Unit*

*August 1988*

Table 6

Projected** Class IV HIV Disease in
King County Residents by Risk Category
1988 - 1993

| Year's end: | 1988 | | 1989 | | 1990 | | 1991 | | 1992 | | 1993 | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | No.* | (%) | No.* | (%) | No.* | (%) | No.* | (%) | No.* | (%) | No.* | (%) |
| Homo/Bi | 1021 | (85.1) | 1524 | (84) | 2136 | (83) | 2884 | (82) | 3713 | (81) | 4749 | (80) |
| Homo/Bi with IVDU | 112 | (9.3) | 163 | (9) | 232 | (9) | 317 | (9) | 366 | (8) | 475 | (8) |
| IVDU | 22 | (1.8) | 54 | (3) | 103 | (4) | 176 | (5) | 298 | (6.5) | 445 | (7.5) |
| Hemophiliac | 8 | (0.7) | 13 | (0.7) | 15 | (0.6) | 21 | (0.6) | 23 | (0.5) | 30 | (0.5) |
| Heterosexual | 7 | (0.6) | 18 | (1) | 31 | (1.2) | 49 | (1.4) | 92 | (2) | 119 | (2) |
| Transfusion | 16 | (1.3) | 22 | (1.2) | 31 | (1.2) | 35 | (1) | 46 | (1) | 59 | (1) |
| Undetermined | 14 | (1.2) | 20 | (1.1) | 26 | (1) | 35 | (1) | 46 | (1) | 59 | (1) |
| TOTAL** | 1200 | (100) | 1814 | (100) | 2574 | (100) | 3517 | (100) | 4584 | (100) | 5936 | (100) |

*Estimated cumulative number of Class IV cases in King County residents since 6/81.

**See Seattle-King County/Washington State Quarterly AIDS Surveillance Report for 2nd quarter to reference methodology of these projections

Note: It is expected that over time increasing numbers of impoverished people will becomeinfected with the AIDS virus. This is important for planning purposes.

## Estimated AIDS and Non-AIDS HIV IV Cases in Children Under Age 13 in Washington State(a)

Cumulative Totals, Yearly New Cases, and Number of Births With Exposure to HIV Infection

| | 1987 | 1988 | 1989 | 1990 | 1991 |
|---|---|---|---|---|---|
| AIDS, Cumulative (b) | 5 | 14 | 26 | 42 | 62 |
| Non-AIDS P.1 & P.2 (c) | 8 | 21 | 39 | 63 | 93 |
| Cumlative TOTAL | 13 | 35 | 65 | 105 | 155 |
| New Cases | - | 22 | 30 | 40 | 50 |
| Cumlative births exposed to AIDS (d) (infected mothers) | 186 | 300 | 443 | -- | -- |
| New Births exposed | -- | 114 | 143 | -- | -- |

(a) Not available for King County only.
(b) Includes one infant who died with HIV-related disease but did not meet case definition.
(c) Assumes 150% of AIDS cases.
(d) Class Pediatric-0 (P-0), indeterminant infection, includes perinatally exposed infants up to fifteen months of age who cannot be classified as definately infected but who have antibody to HIV. Children with Class P-1, asymptomatic infection, meet one of a list of specific signs and symptoms for pediatric HIV infection as defined by CDC but have no previous signs or symptoms that would lead to classification in P-2. Children in the P-2 classification have signs and symptoms of HIV infection and some may fit the definition of AIDS. (Morbidity & Mortality Weekly Report, DHHS, PHS, April 24, 1987)

Table 8

WASHINGTON STATE HOSPITAL AIDS DATA
DIAGNOSIS TO DEATH

| | 18 MONTHS 1984-1985 | 18 MONTHS 1986-1987 |
|---|---|---|
| AVERAGE SURVIVAL (DAYS) | 210 (7 mos.) | 277 |
| HOSPITAL DAYS | 56.2 | 30.2 |
| HOSPITAL CHARGE/DAY | $602 | $654 |
| HOSPITAL CHARGES | $33,809 | $19,759 |

Table 9

WASHINGTON STATE
HOSPITAL CHARGES AND LENGTH OF STAY
1984 to 1987

| | 1984 | 1985 | 1986 | 1987 |
|---|---|---|---|---|
| NUMBER OF HOSPITALIZATIONS | 61 | 228 | 269 | 374 |
| LENGTH OF STAY | 18.4 | 13.2 | 11.3 | 10.6 |
| CHARGES/HOSPITAL ($) | 13,004 | 9,031 | 6,981 | 6,878 |
| CHARGES/DAY ($) | 707 | 684 | 618 | 649 |

Table 10

METHOD OF PAYMENT FOR AIDS RELATED
HOSPITALIZATIONS

| | 1984 | 1985 | 1986 | 1987 |
|---|---|---|---|---|
| NO. OF HOSPITALIZATIONS | 61 | 228 | 269 | 374 |
| % OF MEDICARE/MEDICAID | 39.4 | 32.4 | 25.8 | 28.6 |
| COMMERCIAL, BLUE CROSS, LABOR & INDUSTRIES | 34.4 | 37.7 | 33.8 | 38.8 |
| HMO | 1.6 | 5.3 | 13.3 | 11.5 |
| SELF-PAY, NO-PAY, CHARITY | 24.6 | 23.7 | 22.5 | 21.1 |

# II. Education and Training for the General Public

## Background Information

The December, 1987 Report of the Governor's Task Force on AIDS summarizes the needs for general public education and provides several policy objectives. The goals identified in the Report for a general education campaign are:

1. To raise the level of knowledge among the public about the transmission of HIV and how they can protect themselves and others from infection, thereby reducing fears.
2. To help the public understand the dimensions of the problem, its complexity and the potential costs (in terms of lives, emotions and dollars) and to enlist support for constructive, cost–effective and humane services.
3. To correct misconceptions, identified in survey data.
4. To project the message that anyone can prevent AIDS – and message of control – to counter irrational fear.
5. To promote the concept of risk behavior rather than risk groups.

The report suggests that information about HIV transmission be explicit; that AIDS prevention messages be linguistically and culturally appropriate to the audience targeted; that sources of information arise from the targeted population as much as possible; that the prevention message be consistent and accurate; that evaluation mechanisms be built into each project; and that a preventive campaign requires a partnership between government, minority and community organizations and private industry.

The responsibility for coordinating state AIDS education and prevention activities resides within the Sexually Transmitted Disease Section (STD) of the State Division of Health, which works collaboratively with community–based programs and public health departments. In King County, an active AIDS Prevention Project is funded through the city, county and Centers for Disease Control (CDC). The AIDS Prevention Project and Northwest AIDS Foundation have been providing AIDS education to the King County community since 1983.

Recommendations of the Governor's Task Force were as follows:

1. Establish and fund general education campaigns aimed at three areas of misunderstanding and promoting these correct concepts:
   - saliva, tears and sweat of infected persons do not infect others
   - virus is not transmitted by insects
   - no risk of getting AIDS from donating blood
2. Establish and fund a campaign to inform the public that excessive use of alcohol, and use of intravenous drugs may put people at risk.
3. Establish and fund a campaign to educate the public that specific behaviors put individuals at risk, not membership in population group.
4. Establish and fund a campaign to encourage volunteerism relative to AIDS efforts.
5. Establish and support a strong AIDS program to coordinate AIDS education campaigns for the general community, and recruit participation by the media, private industry, business, religious and community organizations.

6. Increase funding to state and local health departments to provide AIDS education through community–based projects and organizations.
7. Form a state AIDS/STD Education Advisory Committee.
8. State materials regarding sexual transmission of AIDS must emphasize abstinence and monogamy.

A wide variety of communication which can be used for general education and to promote behavior changes, including:

- media advertising
- news and feature coverage
- pamphlets and collateral material
- telephone information and referral services
- AIDS modules in public schools
- forums, workshops and classes
- individual health education and counseling
- peer support groups
- volunteer participation in AIDS organizations/services.

These recommendations of the Governor's Task Force on AIDS are currently under review for implementation by the State Office on AIDS.

## Current Programs

Many general and targeted AIDS education/prevention activities are currently underway in King County, sponsored by a wide variety of agencies. Some sponsoring organizations include the Department of Public Health AIDS Prevention Project, Northwest AIDS Foundation, American Red Cross, Washington Employers' AIDS Prevention Alliance, University of Washington, People of Color Against AIDS Network, Seattle Counseling Service, Women and AIDS Task Force, Deaf Community AIDS Task Force, Seattle Youth and Community Services, Health Information Network, Shanti, school districts, community clinics and many other agencies.

Some of the major activities sponsored by these organizations include an AIDS hotline that services over 35,000 calls annually, a speaker's bureau that reaches over 18,000 persons per year, targeted campaigns in the gay and ethnic minority communities, presentations in public schools, forums, technical assistance to employers regarding AIDS policies and employer/education programs, education programs for service providers, brochures, directories, education campaigns targeted to women, youth and the deaf, and others. All of the communication vehicles cited in the Governor's Task Force report are used by one or more agencies in King County for AIDS education/prevention.

## Issues, Problems, Service Gaps

**Some major issues regarding general public education are as follows:**

1. Ethnic minority communities (Black, Native American, Latino, Asian) and the blind and deaf communities have not been adequately reached with the AIDS prevention/education message, and higher priority should be placed on outreach to these communities and the development of relevant materials.

2. Targeted campaigns for young people, street kids and women of reproductive age need more attention, while not neglecting a priority emphasis on the gay community and among intravenous drug users.

3. News media need to be better informed regarding AIDS and AIDS services, particularly regarding the fact that behaviors not group identification put people at risk, and how to separate fact from fiction.

4. It is difficult to develop a comprehensive AIDS education program for the general public because there is not information regarding which behaviors they are practicing which may put them at risk for AIDS.

5. Energy that could go toward education is directed to fundraising by organizations attempting to find resources to support their programs.

6. Messages which concentrate on abstinence and monogamy, and do not address safe sex practices, are detrimental to the AIDS education effort.

7. There is not a widely publicized repository for all AIDS education materials developed and used from across the country that community groups can access, nor a comprehensive mailing list of organizations doing AIDS education/prevention activities.

8. Education programs need to include persons with AIDS in their planning and delivery.

9. Homophobia is a major barrier to effective AIDS education/prevention in all populations, including the gay community.

**Actions needed to address these issues include these:**

1. Increased funding should be allowed for AIDS community education efforts, particularly targeting the following groups:

   - ethnic minorities
   - deaf and blind communities
   - street kids
   - youth
   - women of reproductive age

   Activities within these targeted groups should be funded through community–based organizations which relate to each group, and focusing on training of leaders within each group to take a leadership role relative to AIDS. Resources to expand the community education effort in these communities should not detract from the need to continue and expand education efforts in the gay and intravenous drug–using communities.

2. Special educational efforts in the deaf and blind communities should be made and should include a fund for interpreters, use of braille, and videos with sign language.

3. Periodic sessions with the community's news media should be arranged to address specific and general AIDS information and updates, with an emphasis on which behaviors do and do not put people at risk for AIDS.

4. The State should be encouraged to fund a survey that addresses behaviors of the general population which may put them at risk for AIDS (ie, sexual behaviors, drug use behaviors) and to establish baseline data on prevalence of risk behaviors.

5. A cooperative fundraising effort among AIDS education/prevention providers in King County should be developed.

6. AIDS education materials should be developed which address all avenues for lowering the risk of acquiring the disease, including safe sex, and should contain language which is explicit enough to be fully understandable and meaningful to the target group.

7. A community depository for AIDS education materials should be designated and publicized and should be made available to community groups.

8. Education efforts at the worksite should be increased as an efficient means of reaching the general population.

9. Homophobia education aimed at reducing homophobia should be integrated into existing and future AIDS education programs.

# III. Education and Training for Health Care Professionals

## Background Information

The Governor's AIDS Task Force Report discussed the need for widespread AIDS education for health care providers, and this need resulted in the training mandate in the Omnibus AIDS statute. All providers need to be comfortable and knowledgeable consulting clients/patients about AIDS prevention and sexual safety. In addition to this, however, there are other significant training needs among a variety of other providers of health care and services for persons with HIV infection and/or AIDS. The need for these as identified in Seattle-King County are found in the chapters of this Plan. Examples of these needs are:

- Health care providers need to know more about substance use and users and aspects of mental illness and available treatment resources in these areas.
- Substance abuse and mental health counselors need to know more about AIDS and its prevention.
- Many providers of all types need training concerning death and dying and grief counseling.
- Providers serving clients of color, or deaf or visually impaired clients often need special training to understand cultural and linguistic differences and other topics to enable them to deliver care in effective ways.

None of these needs will likely be met through one–time courses or workshops.

## Current Programs

There are many opportunities for various types of education regarding AIDS and its prevention in the Seattle–King County area. However, these are not provided in a way to assure that all needed content is available to those often least able to pay for training, who are the front line workers with PWAs many times unlicensed personnel.

It should be noted that there are two major, federally funded programs with headquarters in Seattle aimed at health care providers regarding AIDS, but these programs target providers in a multi–state area, and are not available solely, or even primarily, to King County providers.

## Issues, Problems, Service Gaps

There is an overwhelming need for all types of training for providers of services to persons who are HIV positive and/or have AIDS.

**Seattle–King County elected not to spend Omnibus Funds on training because of other pressing service needs.**

Some entity at the State level needs to assume responsibility for not only carrying out the statuatory training mandates but also for planning and implementing training programs for unlicensed providers.

# IV. Intervention, Outreach and Education for High Risk Behavior Populations

**For each of the population groups, the following information will be given:**

- Background Information
- Five Year Outlook
- Current Educational Interventions
- Educational Interventions Needed to Fill Gaps
- Current Service Interventions (if applicable)
- Service Interventions Needed to Fill Gaps (if applicable)

## A. Men Who Have Sex with Other Men

### Background Information

In Washington State, ninety percent of all cases of AIDS to date have been diagnosed in males who have had sex with other males. While the vast majority of gay men have already adopted safer sexual behaviors, and gay and bisexual male cases will comprise a **decreasing** proportion of future cases of AIDS, they will continue to represent over 80% of new cases of AIDS over the next five years.

There is evidence that HIV transmission is declining in gay and bisexual men. A recent report from a San Francisco cohort of gay and bisexual men showed a seroconversion rate of 0.7% in uninfected gay and bisexual males, as compared to 5.9% in 1985, a decline of 88%. A concurrent decline of approximately 80% in the prevalence of sexual behaviors associated with HIV transmission was noted. This indicates that gay and bisexual men have already made significant changes in sexual behavior since the early years of the epidemic.

But there are large numbers of men who have not shown a decrease in unsafe sexual behaviors. Multiple factors are involved:

- Men who do not identify as gay and bisexual may not be reached by AIDS education messages
- Closeted men may exhibit denial of own risk
- It is difficult to cause mass behavior change because of the ingrained physical, psychological and social patterns which influence behavior; mass behavior change will not occur until the new behavior is considered normative
- Educational messages that are not culturally and linguistically appropriate to specific populations are not effective
- Ongoing exposure to information and skills–building will be required for the maintenance of behavior change
- Behavior change cannot be achieved unless the undesirable behavior can be replaced by something else.

## Five Year Outlook

Over the next five years, we can expect to see a dramatic rise in AIDS cases among gay and bisexual men, and a rise in the number of those who choose to test and are testing positive. Most research indicates a decrease in seroconversion in gay and bisexual men. Basic education will need to be targeted to younger gay and bisexual men who may have missed the intensive gay community education of the early and mid 1980's. Men of color will also need to be targeted with basic education. There will be a growing need for assistance with maintaining safe sex behavior, and new programs will undoubtedly need to be funded. And clearly, there will be a need for increased services for seropositives and PWAs, an area this report does not touch on. All of the programs listed below are time limited by grants; planning for future funding must take place now, given the clear direction of the AIDS epidemic.

## Current Educational Interventions

A variety of educational programs targeted to men who have sex with other men exist in King County.

## Program Descriptions

**A. The Northwest AIDS Foundation** develops and implements educational workshops for gay and bisexual men. The following types of workshops are offered: Dating 1, 2 and 3, Positive Plus, workshops for people living with HIV, Couples Workshop, Hot Sex Workshops and Safe Sex House Parties, using the Stop AIDS model. NWAF also launches an annual high profile media campaign, and has a condom distribution program.

**Target Audience:** Gay and Bisexual Men (Non-closeted)

**Adequacy:** Currently, NWAf can meet client demands among self identified gaay men. However, the programs at the current funding level can not reach men who are not "out", men who do not read gay community publications, men who are not active gay community participants, men who do not feel comfortable with group sessions, or partners of bisexual men.

**B. The AIDS Prevention Project** staffs a hotline, provides speakers and provides educational materials for gay and bisexual men. The Project's longitudinal cohort "Be A Star" study provides AIDS education to participants via individual counseling and information sessions. The weekly "Dr. Bob" column in Seattle Gay News provides scientifically sound answers to clinical questions readers have about AIDS.

**Target Audience:** Gay and Bisexual Men

**Adequacy:** APP can currently meet the demand for speakers, via Speakers Bureau volunteers, and is at capacity on the hotline when staffed by one person. Study enrollment is open. However, while APP's programs reach non-mainstream gay and bisexual men through general education approaches, APP does not reach these men on an individual basis. Ninety percent of clinic clients, who do receive individualized education and counseling, are self-identified gay and bisexual men.

C. **The University of Washington School of Social Work** provides group counseling and anonymous telephone counseling and education for individuals who are having trouble changing their high risk behaviors.

**Target Audience:** Gay and bisexual men who have trouble changing their high risk behaviors, and who are not comfortable in group or public settings.

**Adequacy:** The capacity is limited to 70 clients, but adequacy cannot be determined as this is also a new program. This program does not reach those who do not have privacy enough to participate. It does not reach those who do not access the advertising. Capacity could be a problem.

D. **People of Color Against AIDS Network** will develop and implement house parties in 1989 for gay and bisexual men of color, educational materials for gay and bisexual men of color, and community outreach to gay and bisexual men of color.

**Target Audience:** Gay and bisexual men of color.

**Adequacy:** Because these programs are just getting underway, adequacy cannot be determined.

E. **The Robert Wood Johnson Foundation** recently founded the "Mod Project", an educational project designed to reduce unsafe sexual behaviors resulting from drug (non-intravenous) and alcohol use. Three agencies are involved in the project: Stonewall Recovery Services, who will be targeting the gay community through a media campaign, lecture series and counseling; Seattle Indian Health Board, who will provide enhanced counseling and outreach; and Seattle Youth and Community Service, who will develop interventions aimed at street youth, a large proportion of whom are gay.

**Target Audience:** Gay and bisexual substance users whose use is interfering with their ability to practice safe behaviors.

**Adequacy:** Adequacy cannot be determined as program is not yet underway.

F. **The Seattle Gay News** publishes educational articles on AIDS weekly. Several other publications regularly publish informational articles.

**Target Audience:** Gay and bisexual men

**Adequacy:** Fairly comprehensive weekly coverage. However, the paper does not reach gay and bisexual men who do not read the gay press.

Though the creativity and magnitude of these endeavors is impressive, they are not enough. There are new audiences to reach and new messages to bring. Because prevention is the only effective program to reduce the spread of the AIDS virus, it must be given highest priority.

## Interventions Needed to Fill Gaps

1. **Media Attention:** Continuing media attention is needed to reinforce messages which have already been given regarding sexual behavior and AIDS prevention. In order to encourage maintenance of safe sex behaviors, media must deliver the message that norms have changed, and that low risk sexual pracitices are "in". Additionally, mainstream media must be accessed in order to reach men

who do not self identify as gay or bisexual, but who are participating in risky behaviors. Television PSAs must be shown during prime time.

2. **Increased Counseling And Testing:** Not all men at risk are being counseled and tested. More AIDS counseling needs to take place with individuals whose sexual behaviors continue to place them at risk for AIDS. Counseling must reach a broader spectrum of gay and bisexual men. It is roughly estimated that only 10 - 20% of the gay men in Seattle-King County have been counseled and tested for HIV.

Testing can be made more attractive to people in the following ways:

a) Publicizing of positive outcomes connected with early interventions for those who are seropositive. Gay and bisexual men should understand HIV as a chronic manageable disease.

b) Making sure gay and bisexual men understand that testing may be completely anonymous, or confidential.

c. Making sure gay and bisexual men understand the non-threatening nature of Washington State's approach to partner notification.

d. Focus media attention on the fact that seropositives can remain healthy for many years, particularly if they learn about health promotion, and disease prevention.

e. In addition to more pre- and post-test counseling, longer term counseling is needed to assist some individuals to maintain safe sex behavior.

3. **Improved Referral Systems:** Along with the promotion of HIV as a chronic manageable disease, we will have an increased need for health care providers who can provide health promotion and disease **prevention** education, as well as treat the diseases associated with HIV. Seropositive individuals need to understand the importance of having an identifiable health care provider who can arrange their care. An information, referral and case management service for seropositive individuals should be in place to help accomplish this.

4. **Needs Assessments and Behavior Research:** Periodic needs assessments and behavior research studies should be conducted to determine whether current programs are meeting the needs of gay and bisexual men, and to identify gaps in programs aimed at promoting low risk sexual behavior. Key points to assess are:

a. The extent to which the individual perceives himself to be at risk.

b. The extent to which the individual is practicing low risk sexual behavior.

c. What programs and services individuals feel they need.

5. **Educational Programs Aimed Specifically at Maintenance of Safe Sex Behavior:** It is well established that the majority of gay and bisexual men have changed their sexual behaviors as a result of AIDS. However, existing programs have dealt with educating men about AIDS and safer sex activities, and have only touched on maintenance of such activities. The NWAF's new workshop series will partially address this, but more new programs need to be developed, and evaluated.

6. **Research on Acceptability and accessibility of Testing and Counseling Services:** Most of the existing services, including counseling and testing services, are operating either at capacity or below capacity. It is crucial that we address **why** these services are not booked solid. Regarding testing and counseling, it is unclear whether the market is saturated or whether more "user friendly" counseling (e.g. different geographic locations, additional hours) would increase the numbers of gay and bisexual men being tested. Because only 10 – 20% of the gay and bisexual men in Seattle-King Coun-

ty have been tested for HIV antibodies, there is clearly more work to be done. The questions that must be answered are:

- Why aren't more people seeking counseling and testing?
- What service configuration would be acceptable to them?

Gay and bisexual men of color are underrepresented in APP counseling and testing encounters. POCAAN's new programs should shed some light on the reasons for this; this new information will impact the planning process. Other programs targeted to gay and bisexual men are experiencing similar problems - inability to attract gay and bisexual men of color and men who do not self identify as gay. All existing and new programs must address this problem.

# B. Substance Users

## Background Information

The connection between intravenous drug use and HIV infection has become increasingly important over the last three years. IV drug use is currently responsible for about one-quarter of all AIDS cases in the United States. In large East Coast cities such as New York City, it is estimated that between 60 and 80 percent of the IV drug users are seropositive. In King County, the rates of seropositivity are not that high; AIDS Prevention Project data estimate that 5 - 7 percent of the county's non-gay IV drug users are seropositive. However, the experience of other cities has shown that rates of seropositivity in IV drug using commmunities can rise dramatically within a short period of time. Therefore, prevention in IV drug users is a high priority for King County. What follows is an analysis of the relationship between HIV infection and substance use, and an examination of the local picture.

### 1. HIV Infection and Substance Use

There are three ways in which the use of substances can put a person at risk for HIV infection and AIDS. First, the sharing of needles by IV drug users is an effective vector for the transmission of the AIDS virus. Second, the disinhibiting effect of substances and impaired judgment resulting from their use can lead to high risk sexual behavior. Third, there is increasing evidence that the use of certain substances weakens the immune system and heightens a person's chance of contracting the virus or of progressing from asymptomatic to symptomatic disease.

With respect to the degree to which substances (including IV drugs and other drugs and alcohol) are used to the point where judgment is impaired and disinhibitions result, a number of studies from around the country suggest that these problems are widespread. In one study, 65 percent of gay people stated that they used alcohol or recreational drugs before or while having sex, and 18 percent reported they were so drunk they would not drive a car. Anecdotal reports from bartenders in the Association of Bartenders Against AIDS have noted unsafe sexual behavior amongst customers who when sober are known advocates of safe sex. Among adolescents polled in a study in northern California, over 50 percent report current monthly or more frequent substance use and indicated such use is tied to other destructive behavior and risk-taking.

Furthermore, HIV infection among IV drug users is of particular concern because the spread of the virus to their sexual partners has emerged as the most common mode of transmission to women, many of whom may pass the virus to their unborn/newborn children.

### 2. The Local Picture

It is estimated that there are approximately 12,000 IV drug users in Seattle-King County. Eighty percent of these are heroin users; it is difficult to ascertain the proportion of other drugs used by the other twenty percent. Heroin is normally injected. Cocaine can be smoked, inhaled or injected, and though exact ratios are not known, it is estimated that cocaine is injected perhaps a third of the time. Those who have died from cocaine in Seattle-King County usually injected it. Methamphetimines can also be injected. The practice of "speedballing" (using heroin and cocaine at one time) is common and further complicates attempts to develop precise estimates of amount of IV drug use. Of great concern with respect to controlling the spread of the AIDS virus, of course, is the degree to which needles are shared by IV drug users. In January, 1988, the SKCDPH Division of Alcoholism and Substance Abuse Services conducted a survey of methadone maintenance clients to independently assess the extent of

intravenous drug use and needle sharing among addicts in this area. A total of 212 clients completed the survey, an 85% response rate. The data indicate that:

- 84% of the clients used drugs intravenously in the past year;
- 79% of IV drug users shared a needle or outfit with others;
- one third shared practically every time they shot up;
- 58% indicated that "almost all" or "most of" the IV drug users they know share needles sometimes;
- only 5% always rinse needles in bleach before sharing; and
- three fourths are afraid of getting AIDS.

Results from this survey underscore the prevalence of high risk behaviors in the drug-using community in Seattle. These findings have been corroborated by an ethnographical study in Seattle in which the IV drug users who were interviewed indicated that sharing needles is a common practice, and the cleaning of needles between sharing episodes was not a reported method of risk reduction.

Several other remarks should be made about trends in drug use in the Seattle-King County area. Analysis of several data sources by the Division of Alcoholism and Substance Abuse Services indicated a steady rise over the last 5-10 years in the number of emergency room episodes, deaths involving these drugs and criminal activities. There are indications from several sources that the use of intravenous injection as a route of drug administration has also been increasing.

Furthermore, among heroin users, ethnic minorities are proportionately represented, both among those mentioned in the emergency room data/base (one-fourth to one-third of them mentioned involved blacks) and among both initial filings and subsequent convictions by the Prosecuting Attorney (among filings, white defendants declined from 76 percent in 1985 to an estimated 55 percent by year end 1988, compared to an increase from 21 percent in 1985 for other racial/ethnic categories to 43 percent by year end 1988). These trends of increasing IV drug use and increasing proportions of minorities among IV drug users are expected to continue into the future.

Although only 13 (2 percent) of the 685 cases of AIDS diagnosed in King County to date have occurred among persons whose only risk factor was IV drug use, another 63 (9 percent) were identified in persons who are IV drug users and had additional risk factors, primarily male homosexual behavior. Seroprevalence data, however, indicate that more IVDU-associated AIDS cases will be forthcoming. Of 3,372 clients seen at the AIDS Assessment Clinic from June 1986 through December 1987, 617 (18 percent) are IVDUs. While only 7 percent of IVDUs who reported no male homosexual contact tested positive for HIV antibodies, more than a third (36 percent) of 236 gay males who also use IV drugs seen at the clinic were seropositive. From the use of a standardized encounter form completed for all clients, further information about the Seattle-King County IVDUs has become available. For example, we know that from 63 percent (gay or bisexual IVDUs) to 91 percent (straight male IVDUs) report sharing needles; that 45 percent of females and 38 percent of males have been involved in treatment programs, 72 percent since 1986; and that 57 percent of the clients have used IV drugs in 1987 or 1988. Furthermore, 11 percent report engaging in prostitution (24 percent of the females and 7 percent of the males). In addition, sexual partners of IVDUs seek services at the AIDS Assessment Clinic. Over a third (34 percent) of the 786 women (47 percent of 75 non-white women) seen report having had sex with an IV drug user, and 167 (38 percent of 445 non-gay males (52 percent of 63 non-whites) seen at the clinic report sex with female IVDUs.

Clearly, now is the time to mount a major education and prevention campaign among the drug using population and their sexual partners. (See also the Women and Youths section of this plan for a similar recommendation).

## Five Year Outlook

Over the next five years, we will undoubtedly see an increase in seropositive IV drug users and IVDUs with AIDS. The high rate of sharing needles, and the relative ineffectiveness of treatment programs (discussed later in this chapter), indicate that seroprevalence will continue to rise. Funding for IVDU related programs is currently on the increase; however, the long range picture is unknown. Several programs are just getting underway; careful evaluation of their effectiveness will provide direction in planning future programs. The array of services needed for HIV infected IVDUs will be more complex than those needed for most gay and bisexual men. Therefore, there will be a need for development of new service and education programs, targeted specifically to this population.

## Current Educational Interventions

## Program Descriptions

In reality all clients of alcohol and drug abuse prevention and treatment programs, including those in Alcoholics Anonymous and Narcotics Anonymous, are involved to some degree in AIDS prevention programs. This is to say, all programs whose objectives include prevention or treatment ofsubstance abuse are also AIDS prevention programs. Some programs clearly are more active than others in promoting awareness of the connection between substance abuse and the development of AIDS. These include the AIDS education and brief risk intervention counseling that is being provided for all clients at Cedar Hills Alcohol and Drug Treatment Center, the King County Detox Program, the North Rehabilitation Special Detention Center, and the ADATSA Assessment Center. All of these are operated by the King County Division of Alcoholism and Substance Abuse Services (KCDASAS).

**A. Evergreen Treatment Services** has a grant from Northwest AIDS Foundation to do pre- and post test counseling at its Midvale Treatment Center, a methadone maintenance center.

**Target Population:** Individuals in treatment.

**Adequacy:** the current number of individuals involved in substance abuse treatment programs in King County are hard to determine because of a problem with the information system used to capture this information. In 1986, there were 4875 persons in treatment programs in the County. It is evident that need exceeds capacity, particularly where reimbursement for State supported clients does not equal program costs, and treatment programs cannot afford to treat more State supported clients.

**B. Stonewall Recovery Services facilitates** alcohol/drug awareness groups designed for persons with HIV infection, ARC and AIDS who are seeking to change or control their use of substances. These groups are not for IV drug users.

**Target Population:** HIV–infected persons who are seeking to change or control their use of substances.

**Adequacy:** Because of lack of widespread advertising, this program may not be attracting all the people who need help.

**C. The AIDS Education and Training Center for the Division of Alcohol and Substance Abuse Services** trained twenty drug and alochol counselors, and these counselors in turn each held three

training sessions which provided initial AIDS training for the majority of alcohol and drug treatment clinicians in King County.

**Target Population:** Drug and alcohol counselors.

**Adequacy:** It will be difficult to train all drug and alcohol counselors. The State Bureau of Alcohol and Substance Abuse is developing a regional train-the- trainer model to increase the number of counselors who are trained. Because of the high turnover in this field, it is difficult to ensure that all counselors are adequately trained.

D. **Stonewall Recovery Services and Northwest AIDS Foundation** sponsor a once-a-month lectures by experts on issues related to substance use and AIDS.

**Target Population:** Geared to a lay audience.

**Adequacy:** The lecture series is not widely advertised, and only serves those who are truly motivated to seek help.

## Bleach Distribution

These agencies facilitate the distribution of bleach and condoms: The AIDS Prevention Project, Division of Alcohol and Substance Abuse, and Seattle Youth and Community Services.

- All publically funded alcohol and drug treatment programs have received supplies and training from the Division of Alcohol and Substance Abuse Services to make bottles of bleach and condoms available to their clients. In reality the programs have responded differently to this initiative with some actively promoting bleach and condom availability and others not.
- The AIDS Prevention Project's Lifesavers campaign pursues both passive (the materials are available and easily accessible in locations frequented by drug users) and active (workers on the street pass out the materials) approaches to bleach and condom distribution. Started in January, 1988, this program is scheduled to expand to make bleach and condoms widely available to high risk behavior populations.

A. **Seattle Youth and Community Services** is also making bleach and condoms available through its mobile van which visits areas frequented by street youth.

**Target Population:** IV drug users who are not in treatment and/or frequent the streets.

**Adequacy:** A comprehensive distribution plan (135 sites) has been established by the AIDS Prevention Project. However, the plan has not yet been fully operationalized. As stated above, there is considerable variation among the responses of agencies to these programs. Therefore, more manpower is needed to work with the programs who are not as enthusiastic. Further information on adequacy will be available as the plan is operationalized. This program only reaches IV drug users who are on the streets, or who are in contact with various community agencies. It may not reach the more closeted IV user, or white collar user.

**Needle Exchange.** A needle exchange program run by **ACT-UP** began in late March. Needles are exchanged, and educational materials, including Lifesavers Packets, are distributed to needle exchange clients. SKCPHD plans to take over the needle exchange in May, and will provide paid staff.

**Target Population:** IV drug users who share needles.

**Adequacy:** Although the needle exchange is less than one month old, between 40 and 60 needles are distributed per two hour shift. As popularity increases, there will be a need for expanded staffing and hours.

In addition to the programs described above, funding has been secured for three new programs aimed at preventing high risk behavior related to substance use. Start-up is anticipated in spring of 1989; therefore, adequacy and gaps cannot be determined.

The Seattle-King County Health Department has been awarded funds from the National Institute of Drug Abuse to place three Community Health Outreach Workers (CHOWs) and three community organizers in two Seattle neighborhoods. This is a major intervention that includes HIV counseling and testing, and case management services for IVDUs with AIDS provided by NWAF. An extensive evaluation component will assess the success of the program.

The People of Color Against AIDS Network (POCCAN) has received funding from the Office of Minority Health for a community-based educator in the people of color communities. A portion of the educator's time will be spent on bleach/condom distribution.

The Seattle-King County Health Department received funding from the Robert Wood Johnson Foundation to develop programs in the gay community, among delinquent adolescents and in the Indian community in Seattle aimed at preventing high risk sexual behavior among individuals whose judgment has been temporarily impaired due to the use of alcohol or recreational drugs. The "Mod Project" is described in detail in Section A, Current Educational Interventions.

## Education Interventions Needed to Fill Gaps

### 1. Accessible Aids Education and Prevention Programs

A variety of interventions must be developed to ensure that all IV drug users who are sharing needles have access to AIDS education and prevention programs. Some of the approaches which could be used are to deploy Community Health Outreach Workers (CHOWs) to work on the streets following the successful model used in San Francisco; to continue ethnographic research to learn more about users and use; and to place drug treatment counselors in AIDS testing and case management programs and in low income health care sites, the jail and other settings which see drug users. Funding has been secured to deploy CHOWS; the other areas must be addressed now as well.

### 2. Consistent High Quality Training for CHOWS

A lead agency is needed to assure coordination and quality in the use of CHOWs in Seattle-King County. Several separate agencies and organizations will be placing CHOWs on the streets in Seattle-King County to work with the IV drug using population and with street youth and prostitutes. It will be important that all programs be successful by using trained CHOWs, assuring that they are properly supervised, and so on. It will also be essential that, as CHOWs are deployed by the various organizations, their work is coordinated so that services are not confusing to clients, are delivered efficiently, etc. The AIDS Omnibus Plan Steering Committee endorsed the Health Department's AIDS Prevention Project as the lead agency for AIDS Control with primary responsibility of recruiting, training, supervising and coordinating CHOWs sub-contracted to Group Health Cooperatives Center for Health Promotion. A CHOW consortium has been developed with widespread community representation to participate in evolving the CHOW program. This consortium must have the resources to continue.

### 3. Consistent Training of Health Care Providers and Drug and Alcohol Counselors

Health care providers often know very little about IV drug use and how to work with persons who use IV drugs; at the same time, drug treatment counselors often know very little about AIDS and are uncomfortable talking with clients about issues regarding sexuality. One effort which will address this

problem is that the State Bureau of Alcohol and Substance Abuse is to design a curriculum and train all qualified alcohol and drug counselors about AIDS to meet themandatory training requirements in the AIDS legislation.However, regional resource individuals are needed to provide follow-up, and BASA is not able to fund these positions. Training for health care providers regarding IV drug use and users is needed, and has only been addressed by some agencies and health organizations who have chosen to take on the training for their staff.

**4. Development of Culturally Sensitive, Relevant Programs**

All persons working with substance users need to be culturally sensitive and attuned to issues such as fear of being deported, fear of having one's children taken away, etc. Programs must also be developed to eliminate the language barrier problem.Furthermore with regard to methadone treatment, if the maximum allowable number of treatment slots get filled up, a mechanism is needed to add slots. State law allows a maximum of 350 treatment slots in each clinic. This is reasonable and need not be changed. The law also says each county can regulate the number of clinics. In King County four clinics are allowed, making a total of 1400 slots available. To add clinics would require a change in the County ordinance. Since the prevention of AIDS is, first and foremost, a public health problem, it may be worth considering changing the State codes to allow the local health officer to increase the slots. This could help address a related problem in King County which is that several nearby counties do not have methadone treatment available, and King County treatment programs treat many people from outside the County.

The substance abuse treatment system is already so stressed and lacking in capacity to do what is needed to adequately serve its currentitional problems associated with seropositivity and AIDS.

**5. Programs Addressing Needs of Public Health and Drug Treatment Communities**

Programs must be developed to address the conflict between the public health community's perspective on how to stop the spread of HIV (clean your works, don't share needles) and the political/law enforcement/drug treatment perspective on IV drug use (don't use IV drugs at all). There are also conflicting beliefs about methadone: is the goal to keep people away from needles or to use methadone as a transition to detoxification?

One possible action might be to create separate "AIDS Risk–Reduction" treatment location(s) for those whose goal is to practice risk free behavior relative to AIDS infection but who do not intend to become drug free. Reimbursement issueswould need to be reviewed before undertaking the development of such programs. In any case, increased dialogue between those holding varying views about AIDS prevention, IV drug use and treatment, would be useful to see if there is common ground where the needs of all perspectives can be met.

**6. Programs for IVDU Women**

Programs must be developed that address the special needs of IVDU women in treatment and not in treatment. In addition, programs must be developed to work with female partners of IVDUs. This is crucial as we address the issue of seropositive infants and children.

**7. Programs for People using Substances Other than IV Drugs**

The Robert Wood Johnson program will address users of substances other than IV drugs, who often practice high risk sex due to the disinhibiting effects of "getting high" and the impaired judgement which results. This is only a two year program, and will only reach targeted populations (gay and bisexual men, Native Americans and street youth). Resources will be needed for education of a broad cross section of society which uses substances. In addition, resources will have to be allocated to continue the work the RWJ grant will only be able to initiate.

**8. Policy Issues Clarification**

Many of the recommendations hinge on increases in treatment slots (inpatient and outpatient) and changes in reimbursement rules. These are policy issues and may take longer to resolve than the

development of programs. Service providers must come up with innovative strategies that circumvent these problems, while lobbying for overall policy and funding priority changes. In addition, attention needs to be given to determining where and how counseling and testing for IVDUs should take place.

**9. Increase in Treatment Slots**

In general, more of all kinds of treatment alternatives for low income individuals are needed if we are to stem the spread of AIDS due to substance use. More alcohol treatment more intensive outpatient treatment for cocaine use, more methadone slots, and more inpatient treatment at least for some vulnerable groups, such as abused women and adolescents, could all be used. These slots, of course, would be available if reimbursement were adequate to cover the cost of offering the service.

## Service Interventions Needed to Fill Gaps

**1. Outreach To Seropositive IV Drug Users**

Drug treatment programs offering other than methadone treatment are not consistently serving persons who are seropositive, due in part to limited capacity but also because of lack of information and training for staff to alleviate fears regarding AIDS, homophobia, and other areas where staff is uncomfortable. Additional staff training is needed, as well as staff to do outreach to (or work with existing outreach agencies like POCAAN) seropositive IVDUs. In addition to training, staff need to understand the new anti-discrimination obligation.

**2. Increase in Mental Health Services**

Mental health services for people in methadone treatment are insufficient. Since 30% of persons in methadone treatment are diagnosed with mental health problems as well, this is a major problem. Seropositive IV drug users will also have increased needs for mental health services. As is usually the case, reimbursement to mental health agencies for GAU clients is not adequate to cover costs, so they must limit the numbers they serve. Both the State's Division of Mental Health and local agencies should be prevailed upon to see if some solutions cannot be found. If mental health agencies are not willing or able to serve the methadone clients, the service might be offered in the methadone programs, but, again, reimbursement issues would need to be addressed.

**3. Counseling and Testing Sites for IV Drug Users**

Needs assessments must be conducted with the IV community and their service providers to determine the efficiency and efficacy of offering counseling and testing at Health Department sites, or drug treatment sites. A recommendation from the Health Department must be arrived at.

**4. Increase in Inpatient Detoxification Services**

A major component of any effective AIDS prevention/intervention program must be the provision of inpatient drug detoxification services to those wishing to eliminate their drug taking behavior. Locally, the increase in the use of drugs intravenously adds to the pressure to adequately address this need. At present, there are only six drug detox beds funded for all of King County and present demand suggests that a minimum of thirty such beds are needed. A combination of state and local funding must be developed to provide for this increase in beds.

# C. At-Risk Women of Childbearing Age and Their Children

## Background Information

### 1. The Maternal Population

Women at highest risk for HIV and AIDS, that is those who are IVDUs and partners of IVDUs, are difficult to reach and track. There are an estimated 2,400-6,000 IVDU women in Washington. AIDS Prevention Project data indicate that about 50% of local IVDUs share needles. Only about 15% of IVDUs are in treatment programs. In King County in 1986, there were 1876 women in publicly-funded drug treatment programs. Over half of all persons in these programs were under 30 years of age, and 63% dropped out of programs prior to completion. Women IVDUs are seen most often by the medical and social service system when they are incarceratedor when a medical crisis or pregnancy occurs.

Regarding sexual partners of IVDUs, a study in Newark, N.J., found that over half the mothers infected by sexual exposure did not know of risk behavior in their sexual partner and many first became aware of their own infection only after AIDS was diagnosed in their infant.

Potentially high risk women are often found in jails and prisons. Over 6500 women per year are incarcerated in King County. Approximately 200 of these women per year are pregnant. They are at high risk for HIV infection because of their incidence of IV drug abuse, prostitution, and relationships with IV drug users.

Thirteen known HIV-positive pregnant women have been cared for through May 1988 at University Hospital. The risk factors among these women reflect those found elsewhere in the U.S. Four were intravenous drug users (IVDUs); four more were partners of HIV positive IVDUs; two were partners of bisexual men; two had received HIV infected blood; and one had unknown risk factors. The majority of seropositve pregnant women are themselves IVDUs or partners of IVDUs. The estimated HIV seroprevalence in IVDUs increased from 5% in 1986 to 9% in 1989. Thus, the proportion of pregnant IVDUs who are HIV-positive would be expected to have increased as well.

In addition to the projections based on known seropositive mothers, estimates of HIV seroprevalence can be made for specific populations. Based on numbers derived from screening by the Department of Social Work at University Hospital, approximately 100 patients who admit to regular use of heroin, metamphetamine, or other drugs except cocaine, deliver at University Hospital each year. Another 300 patients delivering each year admit to cocaine use, at least one-third of whom use it intravenously. Thus, at least 200 patients delivering at University Hospital are at high risk for HIV infection. Using the present HIV seroprevalence rate among IVDUs in Seattle, now 7%, at least 14 HIV-positive pregnant women would be expected in this group annually. Based on our current population of HIV-positive pregnant patients, a similar number of women with infection acquired heterosexually from drug using or bisexual partners could be expected (i.e. an additional 14). The number of women with transfusion-related infection is expected to decrease. Considering presently available data, a minimum of twelve known HIV-positive pregnant patients per year would be expected to deliver at University Hospital. However, since efforts for screening and identification of these women are being intensified and the seroprevalence in IVDUs is increasing, a greater number are anticipated in the near future, potentially as many as 30-40 per year. The needs of these high-risk women for education, screening, counseling and full information on pregnancy and its risks are great, and they are often not reached by mainstream prevention efforts. Education must be community-based and should occur when these women are most receptive to information. Pregnant HIV-infected women will need case

management for coordination of medical and social services and aggressive follow-up to track health status and needs of both mother and child.

## Pediatric Population

As of December 31, 1988 there were 4 confirmed pediatric AIDSWases in Washington, all in King County. Based on national estimates that 1.5% of all new AIDS cases will be children less than 13 years of age, the State AIDS Surveillance and Prevention Project estimates that cumulative cases in

children less than 13 years of age that meet the CDC definition of AIDS will grow annually from 4 in 1988 to 14, 26, 42, and 62 in 1992. In addition to the confirmed pediatric AIDS cases there are the seropositive infants and children. As with the adult population, it is difficult to estimate these numbers. The estimate is further confounded with regard to infants because HIV infection is currently more difficult to confirm or exclude in infants than in adults. Babies who are born to HIV positive mothers always have detectable antibodies to HIV, but may not be infected. Infants' blood must be tested by culture, polymerase chain reaction and for development of HIV specific IGGs (each available only at Children's Hospital and Medical Center) in order to differentiate infected from non-infected children. These tests are used in addition to standard HIV, Elisa and Western blots.Children's Hospital believes that, based on the current rate of new patients presently at CHMC, they will provide care to the following number of infants over the next three years; 46 in 1988, 74 in 1989, and 136 in 1990. Approximately half of these will need from 2-3 hospitalizations a year. Nationally, the experience is that infants require 2-3 hospital stays averaging two weeks each, per year with 10% of the total infected population being in the hospital at any one time.

Infants born to HIV-infected mothers need intensive case management. Their care will most often be complicated by parental IV drug use and/or HIV infection, low income, homelessness, or abandonment. In order to maintain thesechildren in the family, a case manager is needed to advocate for the family's medical and social welfare needs, includinghousing assistance, medical care and supplies, respite care, nursing assistance, transportation, nutritional assistance,and counseling. Even for the many infants who will go into foster care, similar support and case management will be headed by their foster caregivers.

## Five Year Picture

Over the next five years, we expect to see an increase in seropositivity and AIDS in both women and children. Those hardest hit will be low income families. Basic AIDS education will continue to be a need for these women, as well as programs addressing psychosocial issues related to women and AIDS. Among these are the difficulties involved in communicating with partners about safe sex and AIDS, and maintaining safe sex behaviors. There will also be a need for more support services for affected women. Most programs for women are very new, and have not yet been evaluated. There will probably be a need to test different approaches.

## Current Education Interventions

**Program Descriptions**

Several types of provider education are offered:

**Foster Care:** The DSHS Department of Child and Family Service Foster Care Program is developing expertise among some of its case workers to work with HIV positive foster

children and encouraging other case workers to use these specialists for consultation when placing a foster child.

**Care for Caregivers: The Red Cross "Helping You Care"** course is offered monthly to train those providing non- institutional care and is available for foster care and natural parents of HIV positive children.

In addition, there are several provider networks, established to provide a forum for information sharing, coordination, problem solving and support among those who provide services to women at risk:

Provider Network: A broad-based group of providers in the Seattle area has been meeting in an aim to coordinate services and identify and address service gaps.

**Pediatric AIDS Planning Network**: A group of providers of services to women and children at risk meet regularly.

**Adolescent HIV Planning Group:** A group of providers of services to adolescents at risk meet regularly.

**Target Populations:** Providers of services to high risk women and children.

**Adequacy:** There is still a lack of health care providers to meet the needs of HIV positive women and women at risk. While DSHS caseworkers have been trained, there is a severe shortage of foster families for HIV positive children.

**Program Description:** The Women and AIDS Task Force provides general education and referral to women on as needed basis.

**Target Group:** Women who perceive themselves at risk.

**Adequacy:** The hotline is answered by a machine, which may discourage questions. There is no formal coordinator for the Task Force, and the group's time is limited.

**Program Description:** The Washington State AIDS Omnibus bill mandates that all pregnant women receive HIV counseling when seeking health services.

**Target Population:** Pregnant women.

**Adequacy:** The extent to which this mandate is being implemented is unknown at this time. Clearly, more training is needed for staff who encounter pregnant women and must do the counseling. This counseling does not reach women who do not come in for prenatal care during pregnancy, and becomes increasingly complex for women who come in for prenatal care after their second trimester.

## Educational Interventions Needed To Fill Gaps

**1. Commitment to Policy Development And Advocacy for Children with HIV**: Children with HIV infection and AIDS require timely access to numerous services, some of which have been provided traditionally by overworked, underfunded governmental agencies such as the State Developmental Dis-

ability office. As the number of children with AIDS or HIV increases, there will be an increased burden on these agencies.

Nationally, some ongoing organizations are pushing for policies which allow children with AIDS to receive automatic designation as Developmentally Disabled. In Washington State, this would not result in any benefits for the children so designated.

In Washington State, services for children with AIDS are initiated by caseworkers in the Division of Child and Family Services, which is responsible for placing children in foster homes. Caseworkers develop "exceptional cost plans" for each child with AIDS. Through this plan, services such

as respite care for foster parents or physical therapy for the child can be provided. It is the States' intention to ontinue to use the Division of Child and Family Services (rather than the Division for the Developmentally Disabled) as the conduit for needed services.

It would be important to monitor this process to assure that children receive needed services, and to advocate for change should the process be insufficient. A position within a governmental agency may need to be developed for this purpose.

**2. Increased Provider Education:** Adding an AIDS caseload to Children's Protective Service further burdens an already overstressed system. [Note: not all HIV infected children will be new to CPS; in New York City, 25% of the children who were HIV positive were already known to CPS for othr problems.]

An initial response to this problem might be to provide education for social service professionals regarding HIV, AIDS, its prevention and treatment, and especially resources which are available in the community for their clients.

**3. Increased Education for Women At Risk:** As the previous page indicates, little education targeted to women at risk is actually in place. More education is clearly needed if we are to reduce the number of new infections in women and children. With respect to women, education regarding high risk behaviors is important for those at risk because they are IV drug users or sexual partners of IV drug users. It will be essential that such education be available at locations where at risk women might be found (e.g., in jails, at food banks, in welfare offices, on the street) rather than waiting for them to come to a centralized location. Likewise, educational programs for single sexually active

women and female partners of bisexual men are needed and attempts should be made to offer these in locations where these groups might be found.

Many at risk women deliver babies in area hospitals, and this may offer a prime opportunity to inform them about the system for education and health care monitoring (albeit already too late for the just-delivered baby). On-call workers, perhaps their peers, may be the best way to make contact with women at this time.

**4. Education for Partners of IV Drug Users:**

Reaching the sexual partners of IV drug users, many of whom do not know they are at risk or will not admit it because of fear that CPS will take their children, will pose a particular challenge.

**5. Education and Services for Women Infected via Blood Products:** While planning prevention and treatment for women whose behavior is high risk, it is important to remember that there are still some women in Seattle-King County who contracted HIV infection from blood products and these women will need services over time also.

**6. Increase Legal and Advocacy Services to Seropositive Women:** Legal services and advocacy are needed by vulnerable, low income seropositive women who are having legal problems. The assistance needed is different from the need for estate planning and preparation of wills. Volunteer attorneys willing to help with the latter do not feel prepared nor have the time to assist with these more complicated situations.

## Current Service Interventions

While health care programs are not always oriented toward health education, the following programs do contribute to educating women about HIV and AIDS:

**Program Descriptions:** Several options are available for at risk women and children seeking care:

**1. Care for women:** Most of the care for women at risk, many of whom will be low income, is provided by Harborview Medical Center (outpatient and inpatient), University Hospital and Medical Center (outpatient and inpatient, especially deliveries), Community and Health Department Clinics (outpatient) and by other area hospitals in the Maternal Care program coordinated by the Health Department. Maternity care and family planning services for HIV-positive and drug-using women are available at Harborview Women's Clinic, University Women's Clinic, Columbia Health Center, and Southwest Public Health Center. In Fall, 1988 Harborview will open a Prenatal Substance Abuse Clinic, where women with significant drug problems will be referred. All these clinics funnel into tertiary care at University Hospital.

**2. Care for Children:** Comprehensive medical care for children with HIV infection or AIDS is available and not limited by ability to pay. Primary care for children is available at Harborview Special Needs Clinic and Odessa Brown Chidren's Clinic, both available in the central Seattle area and serving low-income minority patients; at Columbia Health Center in Southeast Seattle; and at Children's Hospital and Medical Center Outreach Clinic. Tertiary pediatric care is provided at Children's Hospital and Medical Center.

**3. Case Management for Pregnant or Parenting Women At Risk:** The Seattle-King County Department of Public Health, Seattle Division, has received HRSA funding to support one of three requested case management teams which will work with HIV positive and drug using pregnant women and their infants.

**4. AZT Program for Children:** Children's Hospital and Medical Center will soon be participating in several federally-funded treatment research programs which will provide zidovudine (AZT) to infants and children. CHMC zidovudine will be the only provider of such therapy for children in the Pacific Northwest.

**Target Population:** High risk women and infants

**Adequacy:** The SKCPHD case management program is currently building its caseload. Projections indicate that additional case management teams will be needed within two years. In addition, there are few private physicians who provide obstetrical and general health care to uninsured or Medicaid women. Harborview clinics (Women's Clinic, AIDS Clinic) are generally booked far in advance, indicating a clear need for more providers.

## Service Interventions Needed to Fill Gaps

**1. Increased Respite Care:** There is a need to provide respite care and other supports for foster parents caring for seropositive children. It will be especially important to provide supports to avoid burnout among minority foster parents who are in extremely short supply.

**2. Increase in Pool of Foster Parents:** There is a need for more foster care parents.

**3. Additional Case Management Support:** There are complications associated with treating children through a highly controlled, research program (such as the Children's AZT program) which requires compliance by reliable caregivers who will need to administer doses on time, keep records, etc.

Given that many of the eligible children live in disorganized family situations where one or more parent may themselves have AIDS, additional support will be needed.

Providing Public Health Nurses or other providers to encourage compliance and/or develop a group living situation for children while they are on the research protocol, or for the children and their parents needs to be explored. Transportation and child care need to be available to encourage mothers to access health care for themselves and their children. While it is recognized that need for these services goes beyond the AIDS crisis, it is particularly important that these services be available in situations where conditions are changing rapidly and unpredictably and need immediate attention. Ideally, women could obtain transportation and child care services to enable them to attend support groups also. Besides finding a way to make transportation and child care available, there may be ways that medical care appointment systems could be coordinated to accommodate the mother andchild whenever possible. Case management for seropositive children is essential and will pose special challenges given these conditions:

- it will be very resource intense, sometimes requiring more than one case manager for highly complex situations which are momentarily in crisis;
- children's needs for case management will differ from those of adults and we need to gain experience with managing these differences;
- all children who are seropositive will need case management services whereas case management services for adults to date have been available only for persons with disabling ARC or full-blown AIDS.
- case management for pregnant women is desirable if capacity can be increased; this will increase the mother's self sufficiency.

There is a proposal in the current Drug Omnibus legislation to fund an outpatient treatment and service center for HIV positive mothers and children. This center would address the following:

- Coordinated outpatient care.
- Respite and drop-in day care.
- Psychosocial and case management services.
- Classroom for training parents, foster parents, professionals, etc.
- Centralized administration and data gathering, and policy development.

**4. Continued Coordination of Services:** There will be a need to assure that services for children are highly integrated and coordinated since the children will be seen by numerous providers. Case management and support of the newly formed Pediatric AIDS Network should help address this need. As increasing numbers and types of providers interact with women with HIV infection or full blown AIDS,integration and coordination among providers will become more important. It will be essential for the women to know who is in charge of her care at each step along the way. To date, obstetricians have not been very involved in planning and coordinating the care system for HIV positive women.

**5. Improved Access to Care for Low Income Women:** Greater access to health care and to drug treatment is needed for low income and for pregnant women. Also, drug treatment should be available when women are motivated to enter it (oftentimes just after delivering a baby).

**6. Increased Access to Counseling and Testing:** HIV counseling and testing needs to be offered in locations where women are comfortable. In addition, continued counseling is needed after post-test counseling.

**7. Adequate Lab Facilities and Personnel:** There is a capacity problem with respect to the laboratory facilities and personnel to do HIV cultures on babies to determine presence or absence of HIV infection. This process is resource intense and at present only allows for one culture a week. The need for cultures will increase over time.

## Hemophiliacs

There are approximately 400 patients being followed at the Hemophilia Program of the Puget Sound Blood Center. About 25% are seropositive. Programs are as follow:

**Program Description:** The Hemophilia Program at the Puget Sound Blood Center follows approximately 400 patients inWashington with congenital bleeding disorders; 40% of these patients are under 21 years of age. Approximately 90 patients have HIV infection. The program, under federal and tate support, has a full-time AIDS education counselor, and provides AIDS education; testing; counseling and family support, both to individuals and groups; consultation for individual schools and school districts; and referrals for parents needing additional services.

**Target Population:** Hemophiliacs and their partners, especially those who are seropositive.

**Interventions Needed to Fill Gaps:** See intervention #5, Educational Interventions Needed to Fill Gaps.

# D. The Adolescent Population

## Background Information

As of December 31, 1988 King County had three registered AIDS cases 13-19 years of age, and 164 registered AIDS cases aged 20-29 years which meet CDC surveillance definition. In light of the long period between infection and clinical symptoms, it is estimated that up to one-third (39) of these young adults became infected during adolescence. As new evidence indicates that the length of time between the exposure to HIV infection and the onset of AIDS may be longer than average (greater than ten years) in younger persons, it will be most important to examine seroprevalence data as they are developed to determine the impact of HIV/AIDS on adolescents. Currently a rough estimate is that as many as 1,000 adolescents in King County may be HIV positive.

Adolescents experience high rates of pregnancy and other sexually transmitted disease, two indicators of consistent sexual activity and poor condom use.

It is useful to break adolescents into two groups when discussing AIDS interventions: street youth and in-school youth. Street youth are defined as adolescents who attend school inconsistently or not at all, and/or live on the streets or in unstable home environments. In-school youth are defined as adolescents who attend school consistently and live in fairly stable home environments.

Although problems of definition make it difficult to describe the population of street youth precisely, King County police estimate that there are up to 10,000 runaway youth in King County annually, with between 600 and 2,000 of these youth involved in street life. Because of the very real possibility of funding cuts to group homes, the number of adolescents on the street may increase dramatically, and another access to ppoint to reaching youths would be curtailed. Street youth engage in high risk behaviors: an estimated 85% are sexually active with the same or the opposite sex, 30% are homosexually active, 50% engage in prostitution, 85% use drugs, and 5% are IV drug users.

Seattle-King County's population of street youth is at high and multiple risk for HIV infection. They are transient, difficult to reach, and lack access to prevention, education, and medical services. Seattle's Human Services Strategic Planning Office (1987) has identified the limited outreach to street youth regarding STDs to be a serious gap in the city's service system. The 300-800 youth in Seattle estimated to be involved in prostitution are a group who especially need education on how to prevent transmission of HIV virus. These young people often perceive themselves to be invulnerable, are isolated, and are wary and hostile to outreach efforts. They are vulnerable to discrimination due to their minority status, poverty, homosexuality, or social class.

In-school youth are also at risk for HIV because of high levels of sexual activity, lack of or inconsistent condom use, multiple sex partners, and lack of knowledge. In addition, in-school youth, like street youth, exhibit typical adolescent behavior, such as sense of invulnerability, experimentation, risk taking, challenging parental authority and searching for a sexual identity.

## Current Education/Prevention Interventions

Programs available for youth in the King County area are described below. Programs for street youth and in-school are described in separate sections.

## A. Programs for Street Youth

**Program Description:** Risk assessment, pre-counseling, HIV antibody testing, and post-counseling are offered in all SKCDPH district offices, its STD Clinic and AIDS Prevention Project, community clinics and Planned Parenthood clinics. These services are available to anyone who requests them. In addition, HIV risk assessment and counseling have been incorporated into the routine care received in family planning, sexually transmitted disease, maternity screening, and prenatal care clinics.

Health Departments are required to conduct pretest counseling, HIV testing, and post-test counseling of all persons convicted of sexual or drug offenses involving needles. Mechanisms to accomplish these ends are being put in place. Street youth will encounter Omnibus Bill requirements if they become pregnant or are adjudicated of certain offenses. In most situations, however, counseling and testing is not pursued by street youth. While good counseling is a valid educational intervention, testing may have some negative consequences (i.e. a negative test result may make some youth feel invulnerable).

**Target Audience:** In-school and street youth at risk for HIV infection.

**Adequacy:** Currently, counseling and testing centers are operating at or below capacity. While counseling and testing offer youth an opportunity to discuss their concerns and receive AIDS education one-on-one, many youth do not avail themselves of these services, for a variety of reasons (e.g. not wanting to be associated with the gay or IV community).

**Program Description:** Seattle Youth and Community Services and the University of Washington's Division of Adolescent Medicine have programs which are aimed at street youth and those in detention. One program consists of two or three sessions led by an experienced AIDS and youth specialist. The sessions cover basic information, transmission and prevention, as well as safe sex demonstrations. A person with AIDS also addresses the youths.

**Target Audience**: Street youth and youth in detention facilities.

**Adequacy:** Currently, the demand for these SYCScan manage. APP staff have assisted the SYCS staff, but there are many youth in institutions who do not receive AIDS education. Because of the high turnover in detention facilities, some street youth are never reached. Also, there are not enough staff to cover all the area where street youth might congregate.

**Program Description:** SYCS also runs a street outreach program. Staff drive a mini van to areas frequented by street youth, and offer AIDS educational materials, condoms and coffee. There is also an opportunity to talk to an outreach worker about concerns.

**Target Audience**: Street Youth

Adequacy: Because there is only one van and limited staff, not all street youth are impacted by the program. The van project does not reach street youth who spend most of their time in motels or who are heavily controlled by their pimps.

**Program Description** The Coalition for Peer Education is a multi-agency coalition that has developed a peer education project for street and in-school youth. Experienced youth workers will train youth to be peer AIDS educators; these youth will be required to do AIDS education with their peers. Street youth will be paid for their work with the project. The project will kick off in January 1989.

**Target Audience** Street youth and in-school youth.

**Adequacy:** Program has not yet begun; adequacy cannot be determined. However, staffing for the program is inadequate (.5 FTE Coordinator).

**Program Description:** El Centro de la Raza has a full time peer educator who is bilingual. She spends time on the street doing education with Hispanic youth, and provides AIDS education presentations to a varierty of groups.

**Target Audience:** Hispanic street youth

**Adequacy:** There is only one peer educator; thus some street youth are not reached. This program does not reach Spanish-speaking youth who are not on the streets, but who also do not have access to AIDS prevention information. It also does not reach street youth who work out of motels. In addition, little is available for Spanish speaking youth in detention settings.

**B. Programs for In-School Youth**

**Program Description:** The Seattle School District offers an AIDS Awareness Program in its schools, and CDC grants to the state and King County provide for school-based AIDS education. DPH has incorporated prevention information into its F.L.A.S.H. sexuality curriculum for middle and high school use. DPH Family Planning health educators train teachers in the use of the curriculum and do guest presentations in classrooms and for

parent groups. Speakers from the DPH AIDS Prevention

Project address school groups, and the Project plans to hire a staff member to help the more than 100 school districts in the state plan their education programs. School group speakers from Planned Parenthood address prevention of AIDS in their presentations.

**Target Audience:** In school youth

**Adequacy:** Although all students are reached with some AIDS education, the number of hours varies according to teacher. Some students do not learn well in large group settings, and these programs do not provide one on one interactions.

Program Description: The Coalition for Peer AIDS Education is a multi-agency coalition that has developed a peer education project for street and in- school youth. Experienced youth workers will train youth to be peer AIDS educators; these youth will be required to do AIDS education with their peers. Street youth will be paid for their work with the project. In school youth will not receive compensation. The project will kick off in January 1989.

**Target Audience** Street youth and in-school youth.

**Adequacy:** Program has not yet begun; adequacy cannot be determined. However, the staffing of the program is inadequate (.5 FTE Coordinator through 1989).

## Education Interventions Needed To Fill Gaps
## Introduction

An intervention strategy for high risk youth, whether on the street, in school, orin unstable home environments, must consist of more than a one-time educational session. Adolescents have many issues and factors which complicate education and learned behavior. These include lack of education, ashort-term outlook on life, extremely unstable environments (financial, living situation, general healtrh, etc.), the great influence and reliance on peers for information and standards of behavior, influence of drugs and alcohol, etc.

An overtall intervention strategy must include support and short- or long-term counseling with a stable adult wherever possible. This combination of education and support andcounseling should occur at every education orservice point encountered by youths, including schools, group homes, detention facilities, youth service agencies, recreational facilities, etc. The education, support, and counseling should include a focus on sexuality and use of alcohol/drugs, as well as on AIDS and risky behavior.

## A. Street Youth

**1. Runaway Youth Interventions:** Many youth from outside Seattle-King County who come to "the city" know little about AIDS and its prevention. They also are not always familiar with community resources. Many strategies could be devised to reach these youth (i.e. posters in bus terminals, more condom availability with packaging which shows how to use them, and a phone number to call for more information on low risk behavior). In addition to efforts in King County, other counties must also be urged to do their part.

**2. Additional, Targeted Programs:** There is a need for more prevention and education programs aimed at street youth. These programs will need to target different subsets of street youth if they are to be effective. Among the groups are the following and they may be reached in shelters and other locations besides on the street:

- Street Youth Who are homeless, but not regular prostitutes.
- Street Youth who are IV drug users.

- Street Youth whose primary function on the street is prostitution. Within this group are the many prostitutes that work the motels and are not on the street, those that become pregnant repeatedly, and those who have power issues with their pimps which make it difficult for them to control the type of sexual behavior they engage in.
- Youth who are cycling in and out of the home who are highly influenced by their temporary presence on the street.
- Youth who are on probation.

**3. Train Existing Youth Service Staff:** Current staff at educational and service points foradolescents need to be prepared to offer the support and counseling called for in the introduction to this section.

**4. Add Qualified Staff and New Positions:** A designated youth and AIDS specialist may be warranted in agencies that primarily serve youth, and in local health departments. In order to be effective, outreach to street youth must be provided by persons who are trusted and non-threatening, and must be provided in places where youth congregate. This model of "curbside" education and counseling requires materials targeted specifically for this group. In that minority youth are both at greater risk for and less knowledgeable about HIV infection than are white peers, targeted approaches must be culturally sensitive. Additional education should be delivered through the youth service agencies that work with many of the at-risk youth before they become runaways or dropouts.

**5. Counseling and Testing:** As with gay and bisexual men, there is a need to determine whether or not the existing counseling and testing facilities are "user friendly". More anonymous testing sites may be needed. In all cases, repeated opportunities for education regarding transmission of the AIDS virus should be available. Further, access is needed to a safe place where information is available and no judgments are made or arrests take place. It is recognized that adolescents are particularly adverse to testing and counseling.

**6. Training Regarding Decisionmaking And Assertiven**ESS SKILLS: Some of the difficulty in promoting low risk sexual behavior among prostitutes is that their pimps and johns often expect the prostitutes to have unprotected sex with them. It is hard for the prostitutes to assert themselves and follow their own preferences in these situations where the power lies with the partner.

Group sessions for females in detention could be used to begin to work on issues of empowerment. Further therapy to understand and deal with why they place themselves in powerless positions in the first place would be useful too.

In addition, pimps and johns must be educated in a place that is safe and confidential.

**7. Institutional Staffing:** AIDS education and prevention activites are needed in all State institutions serving adolescents.

**8. Education and Housing Options for Sex Offenders:** AIDS education and prevention programs are needed for adolescent sex offenders. Also, clarification is needed regarding requirements for mandatory testing for HIV among juvenile sex offenders and IV drug users. The value of mandatory testing among youth needs careful evaluation. Further, if mandatory testing is to take place, seropositive youth should be released to a stable environment such as foster care or a group home, so that they may receiveneeded attention over time and be worked with not to spread their infection to others.

## Service Interventions Needed To Fill Gaps

**1. Basic Services:** Many of the at-risk youth need basic services such as housing, without which they will find it difficult to practice low risk behavior. At a minimum, shelter beds should be adequate to meet needs. The foster care situation needs to be improved.

# B. In School Youth

## Educational Interventions Needed To Fill Gaps

**1. Private School Education:** Private schools, including church-based schools will not have access to the funds and resources dedicated to implementing the public school education portion of the new State AIDS statute. Besides needing assistance with curriculum development, many teacher who will need to teach about AIDS are neither knowledgeable about nor comfortable with the subject. Ideally, AIDS education and sexuality content could become a part of teacher training and recertification.

**2. Education for High Risk Youth Who Are in School:** Youth who are in a phase of experimentation with sex and drugs, but are otherwise "normal" teens, often receive AIDS education targeted to low risk teenagers. In-school education programs that address both low and high risk teenagers must be developed.

**3. Non-Traditional Learning Approaches:** Not all youth in schools learn via traditional teaching methods. More AIDS education programs that utilize alternative teaching methods, such as theater, music, art, computer, etc., should be developed and implemented.

## E. Gay Adolescents

### Background Information

Although gay youth are a subset of the adolescent population described, they deserve special mention because of their vulnerability to exposure to HIV infection. In addition, there are very few programs in place to address their special needs.

While an accurate estimate of the number of gay and lesbian youth in Seattle is unavailable, various studies conductetd over the past 50 years indicate that about 10% of the adult population is gay or lesbian. Most gay and lesbian adults indicate that they first became aware of their sexual orientation during adolescence. Because the teenage years are a time of exploration, discovery and rapid change, the number of teenagers who have questions or concerns about sexual identity is thought to be greater than ten percent.

Thousands of young people in Seattle struggle with issues related to sexual identity, most often in isolation and without access to accurate information and support. Many gay and lesbian youth are subject to discrimination, as well as verbal or physical harassment. The community's failure to accept and reach out to these youth and their families contributes to their vulnerability to such problems as substance abuse, school failure and drop-out, homelessness, abuse and exploitation, sexually transmitted diseases including AIDS, depression and suicide. Many gay and lesbian teens live on the streets because of family rejection; they are vulnerable to prostitution and IV drug use.

Clearly gay youth are of special interest to those who plan AIDS prevention and education programs. Yet they have not been highlighted. They often do not label themselves as gay and lesbian, and are not easy to access. Although they do receive in-school education, there is a clear need for targeted education programs.

### Five Year Outlook

There will be a continuing need for basic AIDS education for gay youth, as well as a continuing need for support systems. The connection between family and peer rejection, and life on the street is well established, and as was recommended by the Seattle Commission on Children and Youth, early support systems in schools and agencies that come in contact with youth must be implemented.

### CURRENT EDUCATIONAL INTERVENTIONS

**Program Description:** The Youth Eastside Services Bureau and The Metropolitan Community Church run gay youth rap groups that provide AIDS education. They are operated on a walk in basis, and provide a forum for open discussion on a variety of issues.

**Target Population:** Gay adolescents.

**Adequacy:** The drop-in groups do not operate at capacity; it is difficult to recruit youths for the groups.

**Program Description:** AGLYA operates a hotline and provides counselor training to people who work with youth.

**Target Population:** Gay youth and those who work with them.

**Adequacy:** This program has limited funding, and the scope of its work is limited.

## Educational Interventions Needed to Fill Gaps:

**1. In-school Programs That Address the Needs of Gay Youth:** As the Seattle Commission on Children and Youth report points out, curricula that acknowledges homosexuality in youth is essential to the promotion of safer sexual behavior.

**2. Training of Youth Service Workers and Teachers:** Additional training is needed for those who work with youth. SYCS is developing a training program for youth service bureau staff that could be used widely.

**3. Additional Advertising of Services Available to Gay Youth:** There has been limited advertising of the services described above.

# V. High Risk Intervention, Outreach and Education for Minority Populations

## Background Information

While there are people of color represented in all cuts and categories of populations which are at risk for or already infected with the AIDS virus, there are reasons to devote special attention to people of color as a separate group. These reasons are as follow:

- People of color are overrepresented among a) the low income population in the County, b) numbers of persons treated for drug offenses and, c) numbers of pregnant adolescents; and all of these areas are expected to see increased seroprevalence over the next several years.
- In some instances, ethnic minorities are already overrepresented as a proportion of the total number of AIDS cases diagnosed (e.g., Blacks are 5.3% of all diagnosed and 4.6% of total population of King County.).
- There are cultural and linguistic factors within minority groups which inhibit the effectiveness of educational messages developed for a white population.
- In addition, each community of color has particular characteristics which need to be taken into account in order to develop an appropriate AIDS education/prevention program.
- Many communities of color have not recognized AIDS or homosexuality/bisexuality as issues in their communities, and consequently have done little to address these issues.
- Minorities have traditionally had inadequate access to health care, which increases the risk that they will not receive appropriate information about AIDS, or early intervention for those who are seropositive.

In recommending focused attention on people of color, it is not suggested that separate prevention programs be developed in all instances, although these may be appropriate at time.

## 5 Year Outlook

Over the next 5 years, we can expect an increase in seropositivity and AIDS in all ethnic minority groups. There will continue to be a need for basic, targeted AIDS education, as well as services targeted to people of color. Because many of the current programs are just getting underway, it is difficult to predict which will be the most effective. But it is clear that funding must be allocated for the continuation of education programs beyond the grant funding periods, and that special attention must be paid to evaluation now so that future programs can be planned. As with IVDUs, people of color affected by AIDS and HIV may require a more complex array of services than those developed to meet the needs of the gay community. Attention must be given to the development of unique comprehensive services.

## Current Education and Prevention Programs

## POCAAN

Most educational programs targeted to people of color are projects of the People of Color Against AIDS Network (POCAAN). POCAAN was started in 1987 as a project of the American Friends Service Committe and consists of a network of about twenty minority, community-based organizations in King County, Pierce County, Yakima and Spokane. It is the first minority AIDS education organization in Washington State. POCAAN has received grants from U.S. Conference of Mayors, DSHS, Office of Minority Health, NIDA and HRSA to develop statewide, coordinated education and prevention programs targetting the Black, Latino, Native American and Asian/Pacific Islander communities.

Past programs include the "Famous Last Words" advertising campaign funded by the Health Department, the Northwest AIDS Foundation and some private dollars, the publication and dissemination of a comic book on AIDS for use with minority teens, the publication of several brochures targeting Blacks, Hispanics, Asians, and Native Americans, and development and sponsorship of a regional conference on AIDS in Minority Populations which was attended by 300 people. Current programs are as follow:

**Program Description:** Minority Community-Based Education. POCAAN has three full-time community educators who provide education in the minority communities. Educational methods include the dissemination of brochures and other educational materials, street outreach to high risk communities (IV drug users, prostitutes, street youth, etc.), house parties for gay and bisexual men, and women, and distribution of bleach and condoms.

**Target Population:** People of color.

**Adequacy:** These programs are just getting underway, and adequacy cannot be determined. An Asian educator is needed in the Asian communities.

**Community Organization:** POCAAN has a full–time community organizer who will be working with minority community-based agencies to involve them directly in AIDS education and services. In addition, the director of POCAAN is organizing community leaders in Tacoma and east of the mountains to involve them in direct provision of AIDS education and services, and to encourage coalition building among minority community leaders.

This program is just getting underway, and adequacy cannot be determined as of yet. However, it is unlikely that one commmunity organizer can cover all people of color communities, which now represent over 100,000 people in King County.

**Program Description:** NIDA IV drug use community organization project. POCAAN will be hiring two community organizers to work specifically in Rainier Valley to a) educate community leaders about AIDS and IV drug use, and b) to encourage them to work with their communities to develop appropriate AIDS prevention programs. This is part of a large NIDA project which will deploy CHOW workers downtown as well.

**Target Population:** Community leaders and IV drug users. Program has not yet begun; adequacy cannot be determined.

## Other Education and Prevention Programs

**Other organizations providing education to people of color specifically are as follow:**

**Program Description: Sea–Mar Clinic** has been providing home care and chore services to persons with AIDS, and is active in POCAAN in developing educational materials for the Hispanic community.

**Adequacy:** As the numbers of people of color with AIDS grow, Sea-Mar will not be able to handle chore services for everyone. In addition, Sea-Mar provides these services to other populations in need. Sea-Mar is not well known outside of the Hispanic community. Sea-Mar's services are not well publicized.

**Program Description: The Seattle Indian Health Board** has launched a condom distribution campaign using existing funding. The recent RWJ grant application will fund programs at the Seattle Indian Health Board aimed at persons at risk or infected with the AIDS virus among the area's Indian population.

**Target Population: Native Americans.**

**Adequacy:** The RWJ program has not yet begun. The condom distribution campaign is limited due to limited funding.

## Interventions Needed to Fill Gaps

Although the following interventions were delineated with people of color as the focus, points relating to sensitivity to the population served also could be made with regard to the hearing and visually impaired. (The People of Color planning group particularly asked that these populations be remembered as AIDS prevention and service programs are developed).

## Education and Prevention Interventions

1. **Targeted Education:** There is a need to target education and outreach regarding IV drug use and AIDS to minority users and their sexual partners. There are many reasons why a special program aimed toward minority communities is desirable. These include:

- disproportionate number of minorities are arrested and prosecuted for drug related offenses
- educational material prepared for a white audience does not speak to minority audiences
- women of color oftentimes have taboos against discussing sexual issues with their partners and will need extra attention in this regard
- sexual practices differ among the various minority communities and from those of the white and gay male populations

Both CHOWs and community organizers could be used to carry out education and outreach in minority communities. It should be noted that, whenever such workers are used, they should be from the communities they are working with if at all possible. In fact, organizing drug users themselves to do some of the outreach has been an effective strategy in the Netherlands and might be considered here. It will also be important that CHOWs, community organizers and drug treatment staff coordinate and integrate activities if the programs are to be most effective.

Clearly, POCAAN will be addressing some of these people through its targeted education efforts. However, POCAAN's approach is to educate all people of color communities, and the existing resources do not allow for an educator to work specifically with IV users. In addition, funding for the existing educators is limited to one and two years. Ongoing programs must be developed.

2. **Increased Access to Drug Treatment:** Access to drug treatment is an essential component of an AIDS education and prevention program targeted to IV users. Current access is inadequate. Furthermore, too often culturally sensitive counseling and other program attributes which would make treatment appealing and effective are not available. Possible actions could include making available more drug treatment slots for low income individuals and instituting special recruitment and/or training programs to assure that culturally sensitive counselors are available.

3. **Alternatives to Traditional Drug Treatment are Needed:** To reach the widest audiences, a variety of drug treatment options should be available. From a public health viewpoint with respect to the spread of HIV infection, alternatives to abstinence are needed. At the same time, many individuals prefer programs which offer detox and require abstinence. Treatment for substance use and for AIDS

related conditions should be family oriented. Treatment facilities for women need to take into account the home situation and facilitate arrangements for a woman's child/children while she is in treatment.

4. **Increased Education for At Risk Women of Childbearing Age:** Minority women are not sufficiently informed about the sexual behaviors which put one at risk for HIV infection and the potential for passing HIV infection on to a newborn.

One difficulty in delivering this information is that many women do not seek medical care until they are pregnant, and even then there are several problems with delivering these messages to women at the time they come for prenatal care:

- Many minority women never come in for prenatal care.
- It is too late if the woman is already seropositive and pregnant.
- Persons doing the counseling may not be the most appropriate ones to deliver the information unless they understand the culture, sexual practices and taboos, etc., of the clients they are counseling.

Educational programs must be instituted in settings where they will reach at risk women prior to pregnancy. Some options are family planning clinics, WIC, children's clinics, day care settings, beauty parlors, and workplaces. Whatever efforts are directed toward addressing this issue, providers will need training to enable them to do culturally insensitive counseling and be physically recognizable as part of the culture. Counseling and testing services must also be available in these early intervention sites.

Currently, POCAAN will be targeting women through house parties. As mentioned before, there are not enough staff to adequately target women of child- bearing age.

5. **Provider Education:** AIDS phobias among health, mental health and social service agency staffs impede the delivery of good care for at risk individuals and HIV infected patients. Though this is not a minority problem only, it creates more of a problem among minority clients who, many times, are dealing with additional issues such as community denial that AIDS is an issue. Other staff attitudes regarding client lifestyles, sexuality issues, substance use, etc., can be off-putting to clients and affect care delivery. Programs are needed to work with non–minority providers and minority providers. Providers of in-home services for minority PWAs need to include volunteers who are people of color and take into account such things as culturally determined dietary preferences. To attract volunteers it will be necessary for the community to understand that the problem of AIDS is effecting members of their community.

6. **Increased Media Attention to Aids Education:** General education in the various minority communities regarding AIDS prevention and treatment has been insufficient. As this is addressed, the use of local media which reach the target populations will be essential. Media will also need to help in "rumor control" regarding the AIDS epidemic and to help the community to recognize the problem of AIDS. Current media campaigns address women (generically) and those who use drugs and alcohol recreationally.

7. **Continued Attention to Men of Color Who Have Sex with Other Men:** There are gay and bisexual men of color who are not yet fully apprised of sexual behaviors associated with the risk of HIV infection. This group poses a particular challenge because many live at home with families, often have girlfriends, and many are young. Interventions which are personal, such as the houseparty approach where a few friends get together with a health educator may be more successful than widespread community appeals. Programs should not assume that gay and bisexual men of color have the same level of education as white gay and bisexual men. Existing education programs are often inappropriate. As the attention in this epidemic shifts increasingly to IV users, gay and bisexual men of color must not be forgotten as they represent a population at high risk for HIV infection.

8. **Youth of Color:** Educational programs are needed which take into account the premature sexual activity among youth of color. These efforts must interact with existing programs dealing with

parent/child education and must be community based (i.e., sponsored or administered by Urban League or Planned Parenthood or the like). Innovative approaches to this young population, such as the comic book on AIDS recently developed and distributed by POCCAN, should be tried. POCAAN and SYCS have grants to do some of this work, but again, they are time-limited, and a continuing approach is needed as this is a population at high risk for acquiring HIV infection.

9. **Community Education to Address Minority Foster Children with HIV and Recruitment of Foster Parents:** Minority foster children who are HIV positive or have AIDS need to be placed in appropriate homes, but such homes are in short supply even for healthy minority children. While the priority is for an appropriate home, every effort should be made to find such a home for children of color with like minority parents. This importance should not be discounted, though a minority placement may not be attainable in all cases. Groups such as Good News for Black Children and Medina Children's Service should be consulted.

10. **Research Issues:** There are many research issues which need to be addressed in order to maximize effectiveness of AIDS prevention and treatment programs with people of color. Among these, ethnographic studies are needed regarding basic needle sharing practices among the various minority populations; also, a better understanding of the degree of prostitution in the International District and the amount of IV drug use among Indians are needed. Further, finding different teaching skills which work with different groups will be important. A side benefit of research is that transmission of information occurs during research activities.

11. **Responsive Governmental Agencies:** A number of governmental agencies responsible for programs affecting large numbers of people of color have not been responsive to the needs of these people with respect to the AIDS crisis. The Indian Health Service and certain refugee programs have been among those which have not responded in a flexible manner to meet the needs of their users. It would help to have minority representation among staff at all levels of these agencies, especially at the top.

## Services Needed to Fill Gaps

1. **Case Management Services for People of Color:** Case management will be more difficult with multiple problem families. As several members of a family become infected or develop AIDS, new resources will be needed, but current levels of resources to deal with multiple problems are insufficient. Furthermore, to be effective, case managers need to be culturally sensitive, and this will be no small challenge as clients will emanate from diverse backgrounds (e.g., Native Americans and Alaska Natives coming to Seattle from other States for services).

2. **Grief Work in Minority Communities:** More needs to be done regarding grief and grief work in minority communities. In order to grieve, people need to accept what has happened and have permission to relate deaths to AIDS, and this is not possible in some minority communities due to denial. Media exposure regarding the AIDS incidence in a community would promote community ownership of the issue and prepare the way for grief work.

3. **Culturally Appropriate Residential Care:** Residential care which offers a culturally sensitive living environment needs to be developed. Board and staff should include people of color proportionate to the resident population in the facility.

4. **Sensitivity among Health Care Providers:** Management in primary care clinics whose mission is to serve minority populations is oftentimes not bilingual or bicultural. This trickles down and results in barriers to access or, at a minimum, an environment which is not comfortable for clients.

# VI. Prevention And Services For Seropositive Individuals

**Among the most persistent and forceful comments received from the community during review of this Plan were those relating to the importance of including in the Plan a separate discussion of the needs of persons who are infected with HIV but have not developed full blown AIDS. Because the identification of these needs has only recently begun to be articulated and because broad-based community involvement must be sought to prioritize needs and issues and agree on activities needing funding, a fully developed chapter could not be written in time to meet the present deadline. The Health Department is committed to coordinating the development of this chapter over the next several months for inclusion in later editions of the Plan. What follows is a summary of issues and concerns which have been raised to support the need for this chapter.**

Both secondary prevention (i.e. preventing progression from seropositivity to frank AIDS) and services (including case management, counseling and medical care among others) are needed by this population.

Estimates suggest that there may be 20 persons infected with HIV for every one with full blown AIDS. Exact numbers are not known because HIV status is not reportable in Washington State.

Because of confidentiality and discrimination concerns, it is not likely that the names of persons who are seropositive can be known in order to directly offer programs and resources to them individually. However, as evidence increases that there are ways to forestall progression to full blown AIDS, it is anticipated that individuals will voluntarily come forward for testing and, when receiving positive test results, will avail themselves of prevention programs. Among the areas where prevention might be practised are these:

- Zidovudine (AZT) used earlier in the course of HIV-related disease may delay development of AIDS.
- The U.S. Public Health Service will soon recommend routine monitoring of T-cell subsets for all HIV- positive people, and PCP prophylaxis for all people with T4 counts 200 or less.
- There is evidence that use of alcohol and drugs can impair the immune system and prehaps speed progression to frank AIDS.
- Many believe that "healthy lifestyles" including practising good nutritional habits and getting sufficient rest and exercise can delay deterioration in health status.

Among the services needed by persons who are HIV positive is availability of professional counseling. Both persons who are seropositive and social service staff indicate that suicidal ideation and depression are often great for those who have recently learned they are seropositive. Case management needs to begin also at this point when a person begins to explore community resources and develop medical problems. One of the big financial issues, however, is that until diagnosed with AIDS, a person cannot qualify for Medicaid on the basis of disability.

A chapter on needs and services for those who are HIV positive would also need to address how safer sexual activities will be promoted among these individuals both for their own protection and for the protection of their sexual partners.

**JUNE 1989**

# SEATTLE AREA AIDS RESOURCES

## The AIDS Prevention Project (206) 296-4999

(TTY/TDD 296-4843)
Seattle-King County Department of Public Health

Match Services listed below with Agencies on next page.

a Bleach 1, 2, 19, 25, 27, 31

b Brochures 1, 2, 3, 4, 6, 7, 8, 10, 11, 13, 14, 15, 16, 19, 23, 24, 25, 26, 27, 31, 34, 35, 40, 41, 42, 43,

c Case Management 10, 21, 27, 35

d Chore Services/Personal Care for PWA 8, 9

e Condoms, Latex 1, 2, 8, 19, 22, 23, 24, 25, 27, 31

f Counseling 1, 8, 20, 23, 25, 27, 29, 31

g Curricula 1, 7, 5, 8, 14, 40

h Deaf/Hearing Impaired 1

i Dental Dams, Latex 1, 22

j Drug Treatment/Info. 6, 31

k Emotional Support 8, 10, 11, 18, 21, 24, 27, 28, 31

l Experimental or Alt. Treat. Info. 1, 3, 8, 13, 30, 36, 41, 42, 43,

m Financial Aid 8

n Gloves, Latex 1, 22

o Home Parties 2, 8, 19, 35

p Hotline 1, 11, 14, 15, 23, 30, 37, 38, 40, 41, 42, 43,

q Housing for PWA 4,27

r Human Rights 34

s Infection Control 1, 41, 42, 43

t Legal 2, 8, 17, 33

u Library 1, 7, 8, 12, 14, 18, 24, 30, 40, 41, 43,

v Massage Service 8, 16

w Meal/Food for PWA 9

x Needle Exchange 1

y Pediatric 10, 21

z Pets 12

aa Political 2

bb Pregnancy 10

cc Primary Care for HIV+ 25

dd Referral/Information 1, 2, 6, 7, 8, 10, 11, 12, 14, 15, 18, 19, 22, 23, 24, 25, 27, 30, 32, 33, 34, 35, 37, 39, 40, 41, 42, 43,

ee Reiki 26

ff Risk Assessment 1, 25, 35

gg Scientific Articles 1, 8, 14, 18, 24, 30, 41, 43,

hh Sexual Compulsion Treatment 30

ii Slides 1, 5

jj Spanish Language 1, 35, 38, 42

kk Speakers Bureau 1, 5, 7, 8, 12, 14, 17, 19, 24, 30, 35

ll Support Groups 18, 21, 23, 24, 27, 31

mm Testing and Counseling 1, 23, 25

nn Training 1, 2, 5, 7, 14, 23, 27, 28, 29, 30, 34

oo Training for Providers 1, 5, 7, 14, 23, 27, 28, 29, 30, 34

pp Transportation for PWA 9

qq Videos 1, 7, 8, 12, 14, 18, 19, 35, 43

rr Workplace Education 1, 5, 7, 14, 23, 29, 30, 34, 35,

ss Youth/Teen Services 27

1 . . The AIDS Prevention Project (Seattle-King Co. Dept. of Public Health), (206) 296-4999
. . . a, b, e, f, g, h, i, l, n, p, s, u, x, dd, ff, gg, ii, jj, kk, mm, nn, oo, pp, rr

2 . . ACT UP (AIDS Coalition to Unleash Power), (206) 322-2873, a, b, e, o, t, aa, dd, nn
3 . . AIDS Clinical Trials Unit, M-F 8am-5pm, (206) 223-3184, b, l, p
4 . . AIDS Housing of Washington, 8am-5pm, (206) 623-8292, b, q
5 . . AIDS Training Project, M-F 8am-5pm, (206) 543-9750, g, ii, kk, nn, oo, rr
6 . . Alcohol / Drug 24hour Help Line, 24 hours per day, (206) 722-3700 or 1-800-562-1240, b, j, dd
7 . . American Red Cross, M-F 8:30am-5pm, (206) 323-2345, b, g, u, dd, kk, nn, oo, qq, rr
8 . . APLWA (Association of People Living With AIDS), 9am-5pm, (206) 329-3382, b, d, e, f, g, k, l, m, o, t, u, v, dd, gg, kk, qq
9 . . Chicken Soup Brigade, M-F 9am-5pm, (206) 328-8979, d, w, pp
10 . . Coordinated Family Services (Seattle-King Co. Health Dept.), M-F 8am-5pm, (206) 296-5084, b, c, k, y, bb, dd
11 . . Crisis Clinic of Seattle and King County, 24 hours a day, (206) 461-3222 or 1-800-621-6040, b, k, p, dd
12 . . Delta Society, The (Interact. Between People, Anim. and Envir.), 8:30am-5pm, (206) 226-7357, u, dd, kk, qq, z
13 . . FDA (U.S. Food and Drug Admin.), M-F 8am-4:30pm, (206) 486-8788, b, l
14 . . Health Information Network, M-F 9am-5pm, (206) 784-5655, b, g, p, u, dd, gg, kk, nn, oo, qq, rr
15 . . Hemophilia Program (Puget Sound Blood Center), (206) 292-6507 or 1-800-552-0640, b, p, dd
16 . . In Touch (A Community Service Program), (206) 328-2711, b, v
17 . . National Lawyers Guild, Seattle Chapter, (206) 622-5144, t, kk
18 . . PFLAG (Parents and Friends of Lesbians and Gays), M-F 7am-9pm, (206) 282-5004, a, k, u, gg, ll, qq
19 . . POCAN (People of Color Against AIDS Network), M-F 9am-5pm, (206) 322-7061, a, b, e, o, dd, kk, qq
20 . . Project Aries, (206) 543-7511 or 1-800-999-7511, f, hh
21 . . Rise n' Shine, 9am-noon & 2-4pm, (206) 628-8949, c, k, y, ll
22 . . Rubber Tree, The (Zero Population Growth-Seattle), M-F 11am-8pm, Sat 11am-7pm, (206) 633-4750, e, i, n, dd
23 . . SCS (Seattle Counseling Services for Sexual Minorities), M-F noon-9pm, (206) 329-8707
. . . b, e, f, p, dd, ll, mm, nn, nn, oo, rr
24 . . Seattle AIDS Support Group, M-F 9am-5pm, (206) 322-AIDS (2437), b, e, k, u, dd, gg, kk, ll
25 . . Seattle Gay Clinic, T & Th 6:30-9pm, Sat noon-3pm, (206) 461-4540, a, b, e, f, cc, dd, ff, mm
26 . . Seattle Reiki AIDS Project, (206) 282-2203, b, ee
27 . . Seattle Youth and Community Services, M-F 9am-5pm, (206)622-3187, a, b, c, e, f, k, q, dd, ll, nn, oo, ss
28 . . SHANTI, (206) 322-0279, k, nn, oo
29 . . Social Workers NW, (206) 285-7877, f, nn, oo, rr
30 . . STEP (Seattle Treatment Exchange Project), M-F 1-4pm & 7-9pm, (206) 329-4857, l, p, u, dd, gg, kk, nn, oo, rr
31 . . Stonewall Recovery Services, M-F 9am-6pm, (206)461-4546, a, b, e, f, j, k, ll
32 . . Tel-Med (Recorded information), M-F 11am-8pm, (206) 621-9450 dd
33 . . VAPWA (Volunteer Attorneys for Persons With AIDS Legal Referral Project), M-F 9am-5pm, (206) 624-4772, t, dd
34 . . Washington State Human Rights Comm., M-F 8am-5pm, (206) 464-6500, b, r, dd, nn, oo
35 . . Washington State Latino AIDS Coalition, M-F 9am-5pm, (206) 457-7882, (in Yakima (509) 322-7061
. . . b, c, dd, ff, jj, kk, qq, rr

## OTHER AGENCIES

36 . . AIDS Clinical Trials Information Services (NIAID), 1-800-TRIALS-A, l
37 . . Asian AIDS Project, (415) 929-1304, p, dd
38 . . Latino AIDS Project (San Francisco), (415)-647-5450, p, jj
39 . . National Institute of Justice AIDS Clearinghouse, (301) 251-5500, dd
40 . . National Native American AIDS Prevention Center, (415) 658-5613, b, g, p, u, dd
41 . . Project Inform, 1-800-822-7422, b, l, s, u, p, dd, gg
42 . . US Hotline, 1-800-342-AIDS, b, l, p, s, dd, jj
43 . . Washington State AIDS Hotline, 1-800-272-AIDS, b, l, p, s, u, dd, gg, qq

# VII. Availability of Counseling, Testing and Partner Notification

## A. AIDS Counseling And Testing

### Background Information

The AIDS Project was established within the Seattle–King County Department of Public Health (DPH) in 1983 and offered risk reduction counseling, a hotline, and clinical assessment and referral for all clients presenting with any signs or symptoms which could be associated with AIDS. In April, 1985, when antibody testing for HIV first became available, the Project began offering it as well, in conjunction with pre-test and post-test counseling. That May, the Project moved to the Sexually Transmitted Disease (STD) Clinic at Harborview Medical Center (HMC). During the summer the Seattle Gay Clinic began offering anonymous testing, with the counseling component of the program offered by the Seattle Counseling Center for Sexual Minorities. At the same time testing for HIV became available to the entire medical community.

In 1987, the AIDS Project outgrew the space available at the HMC STD Clinic and moved to its own space, adding clinic staff under federal Centers for Disease Control (CDC) funding. The HMC STD Clinic continued to provide counseling and testing with its regular staff both for at–risk persons being seen for STDs, and for low risk clients. DPH district clinics began offering counseling and testing in mid–1987 for low–risk persons.

The State Omnibus AIDS legislation sets forth a number of new requirements relative to AIDS counseling and testing:

- mandatory counseling and testing: persons convicted of three classes of offense under state law – sexual offenses, prostitution or prostitution–related offenses, or IV drug offenses – are required to undergo pre– and post–test counseling and HIV testing (Section 703).
- voluntary counseling and testing: persons arrested for prostitution offenses or drug offenses under state law must be offered voluntary testing and counseling (Section 704).
- AIDS counseling: AIDS counseling must be provided to three classes of people – pregnant women attended by health care practitioners, persons seeking treatment of a sexually transmitted disease, and persons in drug treatment programs (Section 705).
- jail detainees may be ordered by the jail administrator to undergo pre– and post–test counseling and HIV testing if the local health officer determines that the detainee's threatened or actual behavior presents a possible risk to others (Section 706).
- substantial exposure: law enforcement officers, fire fighters and health care employees who have experienced substantial exposure to the bodily fluids of another person may request that that person be required to undergo pre– and post–test counseling and HIV testing (Section 703).

The legislation also stipulates that, except in mandatory testing situations, informed consent must be obtained prior to HIV testing and that test results may be disclosed only to certain individuals. State

Board of Health rules establish the minimum standards for pre–test counseling, HIV testing, post–test counseling and AIDS counseling. Included in these rules is the requirement that pre–test and post–test counseling accompany all HIV testing.

## Current Services

### 1. Actual Testing

At the present time AIDS counseling and testing are available in most public and private health care settings. The DPH's AIDS Project focuses on high risk populations and has two nurse practitioners, and five communicable disease investigators to provide these services. In addition to the sites mentioned above (background section), Planned Parenthood and community health clinics also do counseling and testing for low risk clients. The Puget Sound Blood Bank does routine testing for purposes of safeguarding the blood supply and is required to inform any person whose blood tests are HIV positive. In addition, in Seattle–King County, two private for–profit organizations offer testing, Darmic and Safeguard.

We do not have solid information on the total number of HIV tests which have been done in King County. This is because some blood samples are sent out of state for analysis and because some individuals are tested more than once. During the period 7/1/87 – 6/30/88, 6,710 tests were done at publicly–financed clinics (DPH district clinics and community clinics) and analyzed at the DPH laboratory. The total number of tests analyzed at the DPH laboratory for the same period was 18,766, but even this number represents an unknown portion of all tests. Perhaps an equal number of samples were analyzed by private labs.

### 2. Counseling Standards

Because the Board of Health has only recently issued its rules governing counseling standards, we do not know what portion of the tests given to date were accompanied by pre– and post–test counseling which would meet the standards outlined by these rules. We do know that the DPH has developed and used a protocol for pre– and post–test counseling which is consistent with CDC standards and which meets the Board of Health's standards, as well. The DPH's AIDS Project has become a resource for other organizations seeking advice and information about appropriate counseling.

### 3. Mandated Testing

To date there have been two court–ordered HIV tests in King County; they were for persons convicted of prostitution–related offenses before the Omnibus legislation provisions on mandatory testing even came into effect. During the fiscal year ending 6/30/88, 1,073 persons in King County were convicted of offenses which now could trigger the mandatory testing and counseling provisions of the legislation.

### 4. Required Counseling and Testing

Regarding the counseling and testing which must be offered on a voluntary basis to persons arrested for certain offenses, 5,246 such arrests were made during the fiscal year ending 6/30/88. While voluntary counseling and testing has been performed in the King County jail during this period, only 94 individuals were counseled and only 86 were actually tested. Taken as percentages of the 5,246 arrests, this would amount to 2% counseled and 1.8% counseled and tested.

### 5. Required Counseling

We do not have information on the extent to which AIDS counseling which would meet the Board of Health standards has been available to the categories of persons now required to receive it. We do, however, have estimates of the number of people who must now be provided with AIDS counseling. If the legislation had been in effect last year, the number would have been nearly 40,000 persons, as follows:

Approximately 22,000 pregnant women, assuming that the number of babies born in King County in 1987 represents a fair proxy for the number of pregnant women attended by a health care practitioner.

Approximately 5,400 individuals who were in drug treatment programs during the fiscal year ending 6/30/88.

11,837 individuals who were treated for a sexually transmitted disease during the fiscal year ending 6/30/88.

## Issues, Problems, Service Gaps

### 1. Meeting Omnibus Requirements:

Although large numbers of people have voluntarily received counseling and HIV testing to date, the sheer number of people targeted by the Omnibus legislation for either mandatory or voluntary testing presents some challenges:

Practitioners of all kinds need to be notified of new responsibilities to certain clients;

Counselors will need to be trained;

Systems of quality control for counseling may need to be implemented;

Procedures for ensuring confidentiality will need to be developed;

Tracking systems will need to be implemented so that reliable cost figures can be developed.

Within the jail, criteria need to be developed as to which persons fall within the arrest and conviction categories to be either voluntarily or mandatorily tested. Protocols need to be developed regarding the conditions under which inmates can be required to be counseled and tested due to threatened or actual risky behavior.

Procedures will need to be developed regarding substantial exposure to HIV, including what constitutes substantial exposure and the mechanisms for ordering the testing and counseling which may result from such exposure.

### 2. Access:

Counseling services are currently available in Spanish at the AIDS Project and at some of the community clinics, and in Spanish, Tagalog, Korean and for the hearing impaired at Planned Parenthood. Counseling services are available in other languages through interpreters, although currently this has to be specially arranged. Concerns have been raised about the availability of counseling which is sensitive to the needs and cultures of minority communities, as well as the availability of counselors who are of those communities.

Other concerns about access include:

- the question of whether cost is a barrier to the receipt of counseling and testing services by all who might want them. HIV counseling and testing should be available on a sliding scale fee basis and of no cost to those who cannot pay.
- the question of whether these services are available throughout the County. The Seattle–King County AIDS Policy Task Force (Report July, 1988) recommends that the DPH play a leadership role in expanding access to counseling and testing for people in areas of King County outside Seattle.

Because at present no cure exists for AIDS and there is no treatment which ends infectiousness, the primary purpose of HIV testing is education for behavioral change. Since it is the counseling that

provides the most information and motivation to change high risk behaviors, the CDC sees HIV testing as an adjunct to counseling and considers that testing without counseling would accomplish little in changing behaviors to stem HIV transmission. With this in mind, a major objective should be that as many individuals at risk for AIDS as possible be encouraged to be counseled and be provided opportunities to be tested.

For people whose behaviors have placed them at high risk to be infected, knowing their HIV status offers several advantages. Seropositivity is now being recognized as a chronic disease needing management. If a person is seropositive, early detection of infection alerts that person to get a care provider, to get early care for illnesses which may be serious (fever, cough, etc.), and possibly to qualify for early intervention such as AZT; early detection may prolong life and reduce morbidity and costs. Detection through HIV testing also allows for the notification of unsuspecting partners who may have been infected and for behavior modification so that others will not also be infected. For these reasons as well, then, all people at high risk should have the opportunity to be evaluated and counseled and should have access to testing.

**3. Privately Delivered Services:**

With respect to privately–delivered services where mandatory AIDS counseling is to occur (pregnant women, persons seeking treatment for an STD, and people in drug treatment programs), the DPH has recognized (July l5, l988, AIDS Steering Committee) that it has the following responsibilities:

- assisting in the notification of private providers;
- planning (e.g., convening groups, working with King County Medical Society and others);
- providing referral services;
- promoting AIDS counseling and testing standards;
- providing literature;
- promoting and assisting with hands–on training of providers (recognizing that provider training is required for licensing and relicensing and is the responsibility of providers and licensing boards);
- advocating for the State Department of Licensing or other appropriate State office to implement this part of the State legislation;
- ensuring compliance by DPH contracting agencies.

**4. Summary of DPH Initiatives:**

The following initiatives are set forth in DPH budget documents for the remainder of the l988–89 fiscal year:

AIDS Project:

- 800 new persons at risk for AIDS will be counseled and tested.

STD Clinic at HMC:

- Currently the STD program provides HIV testing and counseling primarily on request. The proposed expansion will provide for mandatory counseling to all ll,500 new patient visits and will provide pre– and post–test counseling and HIV testing to about 25% (2,875 persons) who will elect to be tested.
- In addition, current testing levels (3,380 in l987) will expand as more citizens voluntarily seek theseservices, bringing the total AIDS testing level to 5,500–6,000 in l989.

- Omnibus funds will also fund a full–time position to provide AIDS counseling and testing at the Juvenile Detention Center beginning in January.

Jail Health Services:

- Mandated pre– and post–test counseling and testing for a minimum of 1,368 individuals convicted under state law (estimate from January–March 1988 statistics) and 25–50 individuals involved with exposures of police, corrections, and health care staff.
- Counseling of approximately 6,000 persons arrested for drug crimes/year and over 612 individuals arrested for prostitution; provision of testing to these individuals on a voluntary basis.
- 260 pregnant women and 904 individuals treated for STDs will require counseling (these in–jail individuals are usually from a population at high risk for AIDS).
- Voluntary pre– and post–test counseling and testing to any other jail inmates requesting it or referred by other health care staff.

King County Division and Seattle Division:

- 3,700 pregnant women will be counseled in DPH clinics, and 5% of these (185 women) will be counseled and tested.
- 3,000 new STD visits will involve counseling, and 25% of these (750 individuals) will elect counseling and testing.

Alcohol and Substance Abuse Division:

- 8,000 clients in drug treatment programs will require AIDS counseling.

# VIII. Availability of Case Management Services

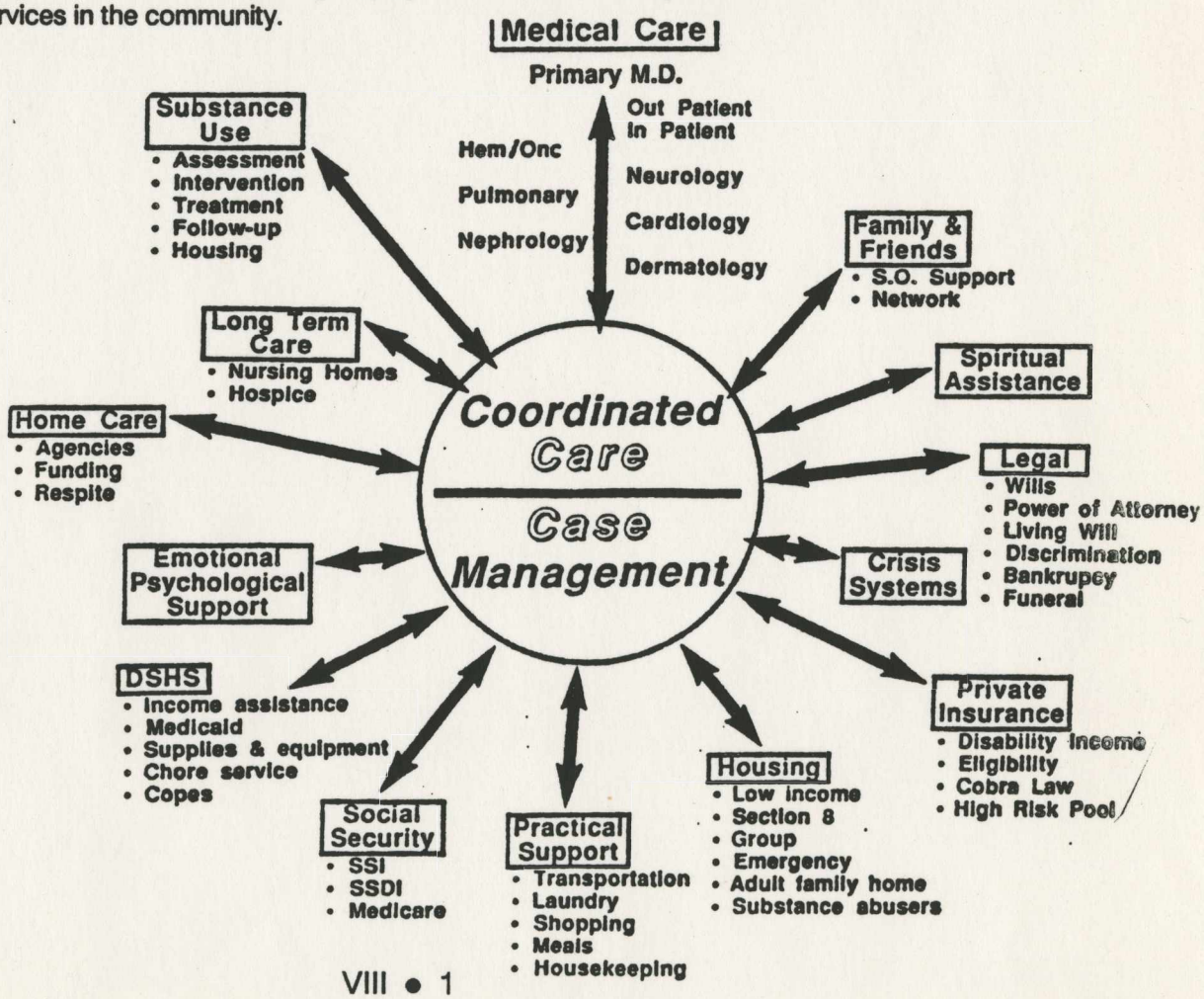
## Background Information

Case management is defined as a system of locating, coordinating, and monitoring a defined group of services and for a defined group of people. Case management focuses on the organization and sequence of services and resources to respond to an individual's health care problem. It is generally comprised of five components: 1) case finding or entry, 2) assessment, 3) goal setting and service planning, 4) care plan implementation, and 5) monitoring and evaluation.

Unlike case management in many other health care areas, AIDS case management is drastically affected by rapid and frequent changes in clients' health status. One consequence of this, for example, is the need for frequent reassessment of client need. It is the aim of AIDS case management to assist clients in maintaining the greatest degree of independence possible consistent with goals relating to cost effectiveness.

An AIDS diagnosis affects all aspects of life. It can result in problems with insurance coverage, finances, housing, and emotional adjustment. It challenges the patient's support systems, beliefs, and financial situation; and it forces sick or weak people to deal with unknown bureaucracies.

An AIDS case manager therefore must have extensive knowledge of the whole panoply of services, agencies and systems shown in the following display. It is the case manager's role to link the client to these types of services in the community.



In Seattle-King County, AIDS case managers were first located at Harborview Medical Center and at the Northwest AIDS Foundation. Over time, several other health care institutions have employed AIDS case managers, and the Northwest AIDS Foundation has negotiated agreements for case management services with certain service providers. There is growing consensus among providers in Seattle-King County that AIDS case management, wherever it is offered, should include a common set of services, and coordination of the complete spectrum of services found in the above display should be available through any case manager. Other forms of care coordination (such as discharge planning in hospitals, medical care coordination in an HMO or service coordination by a home health agency), while sharing many features with case management, do not cover the range of services offered by case managers. At the same time, case management will differ depending on the type of location from which it is offered (i.e. community-based or hospital based); although all services are offered, the emphasis is different depnding on location.

Case management services for persons with AIDS was first funded by Harborview Medical Center in April 1985. In 1986 the City of Seattle funded additional case management services through a contract with the Northwest AIDS Foundation. The 1986 Mayor's AIDS Task Force Report emphasized the importance of case management services, and this consequently became a central theme of major grant applications to the Robert Wood Johnson Foundation and to the Health Resources and Services Administration, both of which were funded in 1987. Negotiations with the State Title XIX program also resulted in an amendment allowing the use of Title XIX matching funds for AIDS case management services. In addition, some institutional providers have contributed funding to support inpatient AIDS case managers in their facilities (see Current Programs below).

Public and grant funds for AIDS case management are funneled through the Health Department in its role as lead agency for development of AIDS services in Seattle-King County. The Health Department has contracted with the NWAF and Harborview Medical Center for case management services funded by RWJ, HRSA, Title XIX, City of Seattle, King County and State Omnibus dollars. The Health Department has emphasized the development of this service at Harborview as the major public hospital and the Northwest AIDS Foundation as the lead AIDS community-based agency. Within this overall structure, however, case managers hired through the NWAF have been placed in both institutional and community settings in the County.

## Current Programs

In 1989, approximately $500,000 is committed to AIDS case management services through the Health Department (more if 1989-91 biennium Omnibus funds are voted by the Legislature). In addition, Swedish Hospital Medical Center supports a full-time AIDS outpatient coordinator and Group Health Cooperative provides some case management through its Community Health Services program. Both University Hospital also offers AIDS case management services. Furthermore, the Health Department will soon fund specialized case management for persons with AIDS who are mentally ill. There is also a special pediatric case management service funded by HRSA and Omnibus funds and offered by the Health Department to infants, children and parents who are patients at Health Department clinics, community clinics or through private providers throughout the County.

Harborview Medical Center employs 2 FTE case managers. One is funded by HRSA through the Health Department, and one is from the Hospital's Social Services Department. Harborview has received allocations from State Omnibus funds for 1.5 additional case managers.plus. The case managers are facility based and do not provide in-home assessments/ visits, but they do provide outpatient case management in addition to inpatient case management and discharge planning and consultation. The Harborview AIDS case managers also provide information and referral for AIDS clinic patients who do not need full case management services.

The Northwest AIDS Foundation employs 5.5 FTE case managers who do provide in-home assessments/visits. In addition, the Foundation provides the equivalent of one FTE case manager offering services specifically for Swedish Hospital Medical Center on an outpatient basis under a working agreement between the two agencies. There is also a part-time AIDS case manager employed by the NWAF housed at Evergreen Care Network to serve persons with AIDS on the Eastside. The NWAF is currently negotiating a contract which will partially support the AIDS care coordination effort at Group Health. The Health Department also supports 1 FTE case coordinator at GHC who does not provide direct client services but coordinates provider services to the clients at GHC.

The Health Department's case management program for infants, children and their parents, supports two case management teams consisting of nurses and social workers.

In addition to its AIDS case management staff, the NWAF provides one FTE information and referral specialist, who screens all clients and determines their appropriateness for case management services. If a client does not need case management, the information and referral specialist is responsible for meeting the client's one-time need. The NWAF also has 3 FTE client advocates who provide support to the case managers in meeting clients' needs (e.g., helping clients fill out public assistance or insurance forms, get to appointments and interviews to apply for assistance, etc.).

The client/case manager ratio at NWAF is approximately 35-40 clients/case manager; at Harborview the ratio is approximately 50-55 clients/case manager with case managers also providing one-time information and referral to other clients (though the Harborview ratio will change when the 1.5 case managers funded by Omnibus dollars are hired). It is estimated that approximately 75% of persons in the Class IV category at any time will need case management services. This estimate may change due to longer life spans resulting from drug therapy and increasing numbers of drug users in the target population. Ideally, case management services should be accessible to those who are non-class IV HIV positive and at high risk of needing the service but realistically there are not enough resources to meet this need. An exception is women of child-bearing age and children who should receive "preventive model" intervention as early as possible.

It is estimated that there will be a need for 25 case managers in 1991, given an average caseload of 45 Class IV clients per case manager. An average caseload of 30 would require 38 case managers. The ideal and/or manageable number of clients is still under discussion. The greater the number of out-of-office responsibilities, the fewer the number of clients a person can serve, etc. Besides needing more case managers, the numbers of client advocates and information and referral coordinators would need to increase to meet growing demand as we move into the future.

## Issues, Problems, Service Gaps

1. It is feared that the cost of providing AIDS case management services may never be fully borne by grants and third party payors and that organizations offering these services will need to subsidize them. There is concern that inadequate reimbursement may result in the need to do more case management from a desk and less in the community.

2. Continuing discussion needs to take place between organizations and agencies around the County interested in offering AIDS case management services to assure that services are a) readily accessible to those needing them and qualified to receive them, b) fully coordinated with the network of AIDS service organizations, and c) defined similarly throughout the County. Expansion of case management services through existing case management providers will be required to meet these conditions.

3. Specialized case management services for defined populations such as those with mental illness and AIDS or pediatric populations will be needed, and the ratio of clients to case managers may need to be adjusted downward to accommodate more complex needs of such clients. In addition, there will be increasing need for case managers from separate systems (e.g., those primarily serving the mental-

ly ill and others primarily serving persons with AIDS) to coordinate their services to assure optimal service to clients and to avoid duplication of services.

4. Client/case manager ratios for similar clientele should be similar regardless of where the service is offered, and further discussion is needed regarding the "right" ratio.

5. Integration of social service case management with the medical case management offered by provider agencies (such as home health agencies, mental health agencies, and the like) is needed. Continuing dialog regarding the differences and similarities of the two foci of AIDS case management needs to take place. The pediatric case management program should offer insights regarding how the two types of case management can be integrated, and proposals to offer nurse consultation to social service case managers should be encouraged.

6. The effect of a Medicaid Home and Community-Based Waiver for persons with AIDS (allowing the use of non-instituional services, in lieu of instituional services) case management will need to be assessed. If the case manager is given some financial control over purchasing services for an AIDS patient, this will place case managers in a different role. It may be harder for them to advocate for clients, and there will no doubt be more paperwork involved in billing.

7. The efficiency and effectiveness of case management will be directly related to the continued growth of volunteer support agencies and the case managers' abilities to work through problems with DSHS, Social Security, the mental health system, drug treatment programs, and the like. Individually, and as a group, case managers need to be adept at identifying and solving systems problems and advocating for development of additional programs and services they see as needed.

# IX. Availability of Services in the Continuum of Care

## A. Outpatient and Inpatient Care

### Background Information

Planning groups in King County have set forth several principles regarding desired attributes of a care system for persons who are seropositive. These are as follows:

- full spectrum of education/prevention, medical and social services (continuum of care) should be available;
- persons with AIDS maintained in least restrictive setting;
- single identifiable medical care manager, available for each person, with coordination between the two care managers;
- inpatient and outpatient care delivered by multidisciplinary teams;
- medical evaluations available to all people who are seropositive;
- social service assessment made when medical care is sought;
- in–home support available with goal to promote care in least restrictive setting, taking into account cost efficiencies and medical appropriateness;
- timely services with emergency response capability;
- a system which is financially feasible to accommodate all people who have need for services.

Two other points which have been made by policy and planning groups are that service provision needs to be shared by providers throughout the County; and that services must be relevant to the populations served and take into account cultural differences and other factors which suggest the need for special services configurations.

### Current Services

Provision of the vast majority of both outpatient and inpatient care is concentrated in a few providers. In a recent survey by the Washington State Medical Association, of 402 physicians surveyed, 4% or 16 physicians, had seen "21 or more" persons with AIDS. If each had seen 21 exactly, these 16 would have seen more than one–third of all PWAs in Washington State (i.e. 336 of 915). Half of the physicians surveyed had seen no PWAs. Within King County the chief providers include Harborview AIDS Outpatient Clinic, physicians associated with Swedish Hospital, Group Health providers, Country Doctor Clinic, the Pike Market Medical Clinic and a handful of other private physicians.

With respect to hospitals of diagnosis within King County, over two–thirds of the diagnoses of AIDS (424 of 622 as of April 1988) occurred at three hospitals – Swedish (211), Harborview (132) and Group Health Central and Eastside (81).

The AIDS Clinical Trials Unit at Harborview, funded by the National Institute of Health, is the only location in the State which has funding to make the antiviral drug AZT and other experimental antiviral treatments

available to HIV infected adults on research protocols. Children's Hospital has recently been awarded funding to offer AZT to children on research protocols.

## Issues, Problems, Service Gaps

1. There are too few primary care providers seeing persons who are HIV seropositive or have AIDS. These providers are too highly concentrated in certain areas of central Seattle. Besides causing a care-availability problem, the providers who are seeing persons with HIV are beginning to burn out and are pulling back from full–time schedules.

2. Though total inpatient capacity in the County should be adequate to meet the additional requirements placed on the system be the AIDS epidemic, Harborview Medical Center is operating at near capacity. Given Harborview's important role in caring for PWAs, especially those with low income, and in carrying out important clinical research, this poses a problem.

3. More geographic distribution of hospital care is needed – especially in the County outside of Seattle.

4. There is not a reliable, up–to–date source of information about qualified and sensitive providers for persons who are seropositive and looking for a primary care provider.

5. There are major shortcomings in the reimbursement system for care for persons with HIV. These include:

- King County has the highest proportion of "self–pay" patients (oftentimes meaning "no–pay" and including HIV seropositives who do not yet have AIDS and cannot qualify on the basis of disability) of any AIDS Region in the State;
- King County has the lowest proportion of Medicaid patients of any Region (probably signalling a lag time before eligibility is established because of the large number of AIDS patients in King County compared to other counties and the backlog in eligibility offices that this creates);
- these situations when coupled with the high concentration of AIDS cases with few experienced providers create for these providers a financially difficult position.

6. Other than through a research protocol with strict guidelines for eligibility, AZT, which costs $700 per month, will not be subsidized for those who need it and do not qualify for Medicaid or have other third party coverage. A one–time federal allocation for such a purpose will be used up in early 1989 by persons currently covered under the program, and is not available to new enrollees after September 1988. This is happening at a time when there are increasing indications that AZT might be effective at preventing disease progression if started earlier among persons with HIV.

## B. Residential Long-term Care

# Background Information

A number of studies and activities have been underway during the past year and a half aimed at defining the types of residential long-term care needed by persons with AIDS in Seattle-King County and putting those alternatives in place. In fact, Seattle-King County has received recognition from around the country with respect to the degree to which the community has attempted to sort through the complex assessment of need for residential long-term care among persons with AIDS.

The studies, coordinated by the Health Department using funds from the City, private grants and the federal government, included a) one which looked at the range of possible residential long-term care options and made recommendations for next steps (Winter 1987), b) another which surveyed persons with AIDS and providers at a point in time regarding the appropriate levels of care those individuals could use were it available (Fall 1987), c) an analysis of the need for a step-down unit for individuals who no longer needed acute inpatient care (Spring/Summer 1988), and d) a feasibility study which has paved the way for construction of a long-term care facility for persons with AIDS and with AIDS-like conditions (Summer 1988). A University of Washington Robert Wood Johnson clinical scholar is also in the midst of a study to follow patients in area hospitals to determine their need for alternative care settings (scheduled for completion January 1989).

To summarize briefly the recommendations of these substantial analyses, there are three actions being pursued to make residential long-term care available for persons with AIDS in Seattle-King County who need it. First, existing skilled nursing homes are being encouraged to take persons with AIDS. Second, a modified version of the State-approved Adult Family Home is being tried on a demonstration basis. Third, plans are being made to construct a 35-bed residential pilot long-term care facility for persons with AIDS and like conditions, to be licensed as a skilled nursing facility.

# Current Programs

At this time there are three nursing homes in King County which are accepting AIDS patients and a fourth to come on line soon for a total of nine beds. All are in Seattle. Just recently all available beds were full for the first time.

A six-bed Adult Family Home, operated and staffed by Community Home Health, opened on June 25, 1988, and was operating at capacity soon thereafter. This facility accepts patients needing all levels of long-term care. DSHS reimburses the facility for each patient on an "exception to policy" basis. The Northwest AIDS Foundation covers the lease costs of the facility. An evaluation component is a core feature of this venture. A second home will be sought with an intent to open it in January 1989.

As indicated in the Background Information section above, the third program being pursued is the construction of a 35-bed long-term care facility. A newly formed non-profit corporation with a broad-based community board is overseeing the development of this facility, which is to be operated by the Sisters of Providence. At the present time, capital costs are being sought with applications to the federal government for grant funding and to the City of Seattle for use of its special levy funds. In addition, private donations will be sought. The facility will provide the complete range of long-term care services which encompass supervised living, skilled nursing care, sub-acute care and hospice or terminal care, and will support the residents in living at a maximum level of independence. The care and services are to include adult day health care as well as respite services. It is hoped the facility can be opened by late 1990.

## Issues, Problems, Service Gaps

1. More beds will be needed in existing nursing homes in Seattle-King County including some in areas of the County outside of Seattle.

2. The cost-effectiveness of the Adult Family Home project needs to determined, and the applicability of this model for special populations such as women and children or substance users needs to be determined. The evaluation component of this project is essential for future planning not only in Seattle-King County but also in other parts of Washington State and other areas of the county.

3. Implementation plans and actions need to continue on the long-term care facility.

# C. Home Care and Practical Support

## Background Information

Hospitalization of persons with AIDS who could otherwise be cared for in a home setting is an extremely inefficient use of resources. Similarly, a long-term facility may be an inappropriate residence. Such a facility can be more expensive than a home care setting because of the exceptional rate of reimbursement that is often necessary for nursing home care of AIDS patients. Persons with AIDS, like the elderly, have indicated a desire to stay in their homes as long as possible, even when they are ill. Advances in medical treatment of persons with AIDS and increased experience in caring for persons with AIDS is likely to lead to less demand for hospitalization, but more demand for monitored care in the home.

A package of services is needed to adequately and appropriately maintain a person with AIDS, who is ill, in his/her home. This service package includes home-delivered or home-prepared meals, transportation to medical appointments, homemaker and chore services, various levels of home health nurse and/or aide care, and various levels of attendant care. Sometimes, the ill person will have a live-in companion (family or lover) who can provide many of these services. If not, case managers can sometimes arrange and coordinate the necessary services through a variety of providers and friends/family. There are also times when there needs to be an attendant in the home with the ill person to provide many of these services and to coordinate those which they cannot provide. Each client who is in this situation will require different types and different levels of assistance for different periods of time depending upon his/her health status and existing social support system. The client's ability to obtain needed services is also dependent on his/her financial resources at the time of illness.

The AIDS case manager is in the best position to identify the various needs of the client in consultation with them, and to arrange for the necessary services from the community. The case manager does a client intake of each client which assesses both service and resource needs already available to the client, including personal and financial resources. The case manager is also trained and experiences in identifying and arranging for community resource assistance. Thus, when the client's situation deteriorates to the point that intensive home care or hospitalization is required, or when the client has been hospitalized but is eligible for discharge, the case manager is in a unique and important position to arrange for appropriate home care services in consultation with the client's primary care physician.

The ability of the case manager to maintain a client in the home as opposed to institutionalization is dependent upon the availability of community resources to fill the gaps in the client's support system. For many persons with AIDS who are young and lack financial and personal support, this can be extensive. The service providers who deliver such services depend upon a variety of resources to maintain their operation, including volunteers, grants, public reimbursement, client and/or insurance reimbursement, and public fundraising/donations.

## Current Services

The Chicken Soup Brigade, started in 1983, has provided the bulk of practical support services to persons with AIDS in the Seattle area. This has been done through the use of volunteers with staff support provided by grant funds. CSB services include meal preparation and provision, help with homemaker/chore services (shopping, cleaning), and transportation. In the past year the CSB has provided more than 15,000 (1988 = 300/week X 52 weeks) meals, 7,934 hours of homemaker services and 2,040 trips to medical appointments and other important destinations. 15,012 hours of volunteer commitment were logged in.

Publicly funded programs have included Chore and Community Options Program Entry System (COPES). The Chore program is not currently available to most persons with AIDS because of strict eligibility criteria imposed by DSHS in order for the program to stay within an inadequate budget. COPES provides in-home care to persons found eligible to receive nursing home care. This is accomplished through a waiver to the State Medicaid program. There are limitations to the usefulness of this program caused by reimbursement requirements and inadequacies.

There are many home health and hospice agencies throughout the County which are able and willing to provide services to PWAs. Again, the problems relate to reimbursement – some types of providers cannot be reimbursed and there is a limitation on the number of units of service which can be provided by other essential providers.

Attendant care which is an essential component for maintaining many of the PWAs in their homes is not available except through a small amount of dollars which were awarded for this purpose on a stop-gap basis by the RWJ and HRSA grants. Attendant care refers to intermittent homemaker/-chore type care provided either around-the-clock for a short period of time or for substantial blocks of time during a day for either a short or long period of time. Current expenditures under these grant programs are running $7,000/month.

## Issues, Problems, Service Gaps

1. Stable funding is needed to provide attendant care.

2. Reimbursement rules, regulations and inadequacies combined make it nearly impossible to configure needed home care and hospice services for many PWAs. A Home and Community Based Waiver to the State Medicaid contract is seen as one way this very major problem could be addressed. Under such a waiver (which is now operating in four states for PWAs), PWAs qualifying for public assistance who need hospital or nursing home care are also eligible to have an equal amount of funds spent each day to keep them in alternative settings such as the home. So far, DSHS has not been aggressively pursuing this waiver. Until the waiver is procured, more stop-gap funding will be required.

3. Recruitment and retention of volunteers to provide meals, practical support services and transportation will be insufficient to keep up with demand. Volunteers who can serve during normal working hours (8:00 AM to 5:00 PM) are and will continue to be in extremely short supply. (See also Nutrition section of this plan)

## D. Individuals with Dual Diagnosis of Mental Health Problems and HIV Infection

### Background Information

Persons with mental health problems and HIV infection actually fall into several distinct groups:

- Those who, as a result of the AIDS virus and related infections have developed central nervous system problems causing mild to severe behavior changes, but who have no history of mental illness. The results can be 1) acute psychotic episodes, which can often be successfully treated and managed with medications, or 2) progressive mental slowing, confusion and dementia which is not as easily treated or managed with medications. **(Category A)**
- Those who have a history of chronic mental illness and involvement with the mental health system prior to being infected with the AIDS virus. These individuals may have lived in congregate care facilities, on the streets, or in their own apartments but not require more support due to their medical problems. In some cases they are persons with an additional diagnosis of substance abuse. **(Category B)**
- Those who have acute mental health problems which stem from learning that they are seropositive, dealing with abandonment of family or friends, facing death and dying issues or from any of a number of other emotional crises. (Category C)
- Those who are developmentally disabled and have become infected with the AIDS virus. **(Category D)**

Individuals in the last three categories may also develop AIDS-related dementia, Category A.

It is difficult to project the numbers of persons in King County falling into each of these categories. With respect to Category A, information regarding the extent of neurological involvement in seropositive individuals to the point it is debilitating is still evolving (see Chapter I). One estimate of the numbers of chronically mentally ill who are also seropositive (Category B) in King County is 650-1040. This figure is based on the projection that approximately 13,000 gay/bisexual men in King County are HIV-positive.

The percentage of chronically mentally ill within the general population is from 5-8%, and there is no reason to believe this figure would differ within the gay/bisexual population. This estimate may, however, be conservative given other high-risk characteristics of the chronically mentally ill. These include sexual confusion, poor judgement, non-assertiveness and sexual vulnerability as well as the increased incidence of multiple partners and same sex activity that may occur in institutionalized or geographically isolated groups.

It is likely that all persons newly diagnosed with the AIDS virus fall into Category C (that is, have a short-term emotional crisis), and, again, when diagnosed with AIDS. Of course, many of these seek support from friends and family and other non-professional sources. Numbers who are seriously acutely ill (that is, are suicidal, severely depressed, etc.), are perhaps 5-10% of the total number of individuals who have been diagnosed as seropositive.

With regard to the developmentally disabled, it is thought that the numbers infected with the AIDS virus in King County are small at this time.

## Current Programs

Recognizing that resources for the dually diagnosed are so lacking (see Issues section following), a task force with broad-based membership from both AIDS and mental health organizations formed in June 1986 and has been working since then to formulate some strategies for responding to the needs of these difficult populations. As a result of the work of this Mentally Ill with AIDS/ARC and HIV Positive Task Force, a small amount of funds were procured by the Health Department from HRSA to develop and implement a voucher program to buy needed intensive case management services, both for the chronically and acutely mentally ill with HIV infection. This program will be implemented by the last quarter of 1988. However, the limited funds available are not expected to meet nearly all the needs (HRSA awarded $22,000 for year one and $27,000 for years two and three of the grant for this program).

The King County Department of Human Resources plans to issue a request for proposals from organizations to provide similar case management services at the beginning of 1989. Hopefully, this program and the HRSA-funded program will dovetail and together begin to address the case management needs.

Intensive case management has been demonstrated to be an effective treatment modality with chronic mental patients. Case management of AIDS/ARC clients has been shown to minimize hospital stays and maximize the development and use of community resources. Combining the knowledge base of case management for the mentally ill with knowledge about AIDS is expected to offer these clients – and the organizations and families willing to provide shelter and mental health services – the support, education and close monitoring that are needed. It is expected that this case management approach will require considerable resources (Intensive case management is expected to cost $600-$800 per month per person for 15 hours of case management).

In addition to efforts to establish intensive case management for the dually diagnosed, other activity related to the needs of these populations has been underway. The King County Mental Health Board – responding to presentations and letters from the Task Force on Mentally Ill and AIDS – included AIDS issues on their 1987-89 Mental Health Plan. Acceptable housing, mental health services, and training programs are listed under Priority Two Objectives. Unfortunately, Priority Two Objectives are not funded under the current budget. Thus, while the County is not able to fund these activities at this time, they do recognize the need and can be called upon for support.

The School of Social Work of the University of Washington received a grant from NIMH for an AIDS Training Project which trains AIDS health care providers. While the focus is oh the psychosocial aspects of caring for PWAs, their training is offered broadly to all types of providers and is not targeted to mental health providers. This program works in conjunction with the AIDS Education and Training Center at the University of Washington which is funded by HRSA and which specializes in the biomedical aspects of AIDS.

Seattle Counseling Services also has grant funds to provide educational programs for mental health providers.

Finally, the Association of Residential Mental Health Providers and the County Acute Care Providers have also expressed interest in issues related to care needs of the dual diagnosed.

## Issues, Problems, Service Gaps

1. The mental health system in general in Washington State is terribly underfunded. As a result, clients who do not meet the State's official priorities often do not get help. Even then, there are long waiting lists for many mental health programs. At this time persons with the AIDS virus who are also mentally ill are not a high priority for services (unless they meet other criteria).

Every effort should be made to establish persons who are acutely, seriously or chronically mentally ill and HIV positive as high priority for counseling at mental health centers. Also, overall funding for the mental health system should be increased.

2. There has been no agency or group of agencies willing to take the lead and be identified as the "mental health AIDS agency."

The response of traditional mental health service agencies to dual diagnosed individuals has been inconsistent, at best. Some do not recognize or cannot respond to the unique needs of this group, while others find themselves spending an inordinate amount of time trying to locate or develop services among providers where fear and ignorance about AIDS and HIV transmission exist. AIDS case management programs, still fairly new themselves, are experiencing growing caseloads (now as high as 50 to 60) and must, by necessity, be geared toward "mainstream" AIDS services.

Case management services specifically for the mentally ill (without HIV infection) are very limited. There are about four programs in the County that provide intensive case management. The waiting list at some is six months to a year. The dually diagnosed needing intensive case management cannot wait this long. Some would be dead by the time their name reached the top of the waiting list.

Besides agency willingness/capability, the dually diagnosed do not fit well into existing services. They are not usually able to function in groups such as AIDS/ARC support groups or groups for the worried well. Traditional therapy approaches are inadequate.

Support should be given to the Intensive Case Management program being developed with HRSA funds and through King County Human Resources which will provide for psychiatric assessment of the dually diagnosed and a team to plan and provide services to the client (team would include mental health professionals and AIDS case managers). These programs should provide important information regarding the numbers needing such services. Current AIDS case managers estimate that 5% - 10% of their caseloads with Class IV infection need psychiatric assessments. The primary problem among these individuals is depression while some are manic depressive and others are exhibiting bizarre behavior. The case managers believe about 5% of their AIDS clients could benefit from intensive case management. Besides these individuals, who must have Class IV infection to qualify for AIDS case management services, though, are a number of street people who are mentally ill and seropositive and not connected to any system.

As more information is gained about actual need, it will be important to institutionalize the intensive case management program for this group of dually diagnosed individuals who, because of disorganization and disorientation, will need supervision if they are to get services they need and be prevented from spreading the AIDS virus.

3. Another barrier to access is that people with dual diagnosis of substance abuse and mental ill-ness seem oftentimes to be screened out of the mental health system until they get their sub– stance abuse under control and out of the substance abuse system until they get their mental health problem under control. When they have the AIDS virus on top of these two problems, they fall through all the cracks.

To begin to address this, representatives from the three types of agencies serving clients with these problems should discuss the issue and develop a strategy for how this "Catch 22" situation might be remedied.

4. Mental health staff need education about AIDS. Most know very little about AIDS and many are uncomfortable talking about sexual behavior with their clients. On the other hand, AIDS service providers are often unskilled in symptom recognition or medication management of the mentally ill and can become frustrated or even disruptive in their attempts to help.

Cross training is needed and must be offered on an ongoing basis as new knowledge is gained about the AIDS virus and mental functioning.

5. Housing and residential long term care, already at a premium for both persons with AIDS and the mentally ill, is yet more difficult to secure for the dually diagnosed patient.

The congregate care facilities and halfway houses set up to provide housing for the mentally ill cannot care for persons with medical problems, those with dementia who wander or those who are disruptive. In addition, persons with AIDS are uncomfortable living in the CCFs. They are afraid of what will happen to them when others living in the house find out they have AIDS. There is currently one CCF with persons with AIDS as patients.

In addition, persons with AIDS are uncomfortable living in the CCFs. They are afraid of what will happen to them when others living in the house find out they have AIDS. There is currently one CCF with persons with AIDS as patients.

There are no intermediate or skilled nursing home mental health beds open to these individuals either.

If an Adult Family project were to be developed to serve this population, it would require very heavy mental health staffing and clearly defined structures and policies for dealing with residents and their problems. The long term care facility which is to be built should be able to accommodate the dually diagnosed, but existing facilities serving persons with mental illness should admit the dually diagnosed and should treat them as they treat other residents.

# E. Nutrition Services

A comprehensive three-year plan for nutrition services was completed in March, 1988, by the Northwest AIDS Foundation. The following material draws heavily on the contents of that plan. For more detail than is contained here, see the NWAF plan.

## Background Information

Nutrition is an important part of the care for person with AIDS (PWAs). Physicians and dietitians indicate that good nutrition can improve a PWAs chance of fighting opportunistic infections and recovering, and may make the difference between a patient's being able to care for him/herself versus one who is bedbound and totally disabled.

PWAs generally lose about 30-40% of their body weight by the time they die. Dietitians have agreed that the complications of AIDS place those with the disease in a high nutritional risk category.

PWAs face many obstacles to eating a nutritionally balanced diet. Lack of appetite caused by disease, depression, fatigue, or drug therapy; lack of energy to prepare meals; lack of money to buy food or nutritional supplements; fear of eating because it may cause diarrhea; painful swallowing; and changes in taste perception caused by disease; medications and malnutrition all contribute to the reduced caloric intake and considerable weight loss seen by PWAs.

Many of the opportunistic infections that PWAs acquire make it very difficult for them to eat. Oral thrush can cause lesions in the oral cavity and esophagus, making it difficult to eat and painful to swallow. Anorexia and nausea may be caused by infections as well as some medications and treatments. Diarrhea can lead to the loss of fluids and electrolytes causing dehydration and electrolyte imbalance. Kaposis lesions can make it difficult to swallow. Gastrointestinal infections and pancreatic insufficiency can often lead to malabsorption.

Chemotherapy, radiation therapy and other treatment regimens can affect an individual's taste, appetite and chemical balance. Some chemotherapies may cause PWAs to be too sick or too tired to eat or prepare food.

In addition to their medical problems, PWAs often face financial obstacles to eating well. Approximately 68% of PWAs in Seattle receiving case management services are living on monthly incomes of less than $400.00. After paying rent and utilities, there is little money left to buy food. Nutritional supplements, needed by many with PCP or wasting syndrome, are often too expensive to purchase. If the PWA cannot afford food or nutritional supplements he/she often goes hungry.

**Among the services needed are the following.**

### 1. Nutritional counseling assessment

From the time an individual receives notification that he/she is HIV-positive, he/she needs to be made aware of the importance of nutrition in maintaining good health. When symptoms related to HIV infection manifest or a diagnosis of AIDS or D-ARC is made, an initial nutritional assessment should be done by a dietitian to develop a baseline of weight and size for the PWA and to assess his/her nutritional status. Ongoing counseling is important to help clients make adjustments in their diet as their illness changes and as they try different drug and radiation therapies. For PWAs who are hospitalized, dietitians should be available as members of the provider team.

### 2. Nutrition Information

An easily accessible source of information about nutrition is needed for those PWAs who are not hospitalized and for caregivers preparing meals for PWAs. These resources would need to be able to provide general information on nutrition, specific diets or food supplements, the effects of certain

drugs on the digestive system, and locations for getting food or food supplements. In addition, these resources could suggest foods that appear to be easy to eat and digest for the PWA with specific opportunistic infections. The food suggestions would need to include nutritional snacks as well as recipes or full meal plans.

### 3. Meal preparation and food service

PWAs' need for help with meal preparation and shopping varies with their health, income and social support system. Some, with limited income, need money to buy food or food given to them; some, who are physically weak or homebound, need help with shopping or meal preparation; and for some, nutritional supplements, such as Ensure, may be the only thing they can eat. For the PWA with a low income costs are prohibitive. Those who cannot care for themselves need fully prepared meals.

### 4. Training and education for health care providers and caregivers

Over the past few years, the vast majority of PWAs in King County have received their hospital care in a few Seattle hospitals. The dietitians at these hospitals have developed, on their own, preliminary guidelines for responding to the nutritional needs of PWAs. Most of the current nutritional information related to AIDS is based on the clinical experience of those dietitians who have been treating PWAs for some time.

As we move into the future and the number of PWAs increases, more hospitals, home health agencies and nursing homes will be caring for them. Dietitians, both hospital based and community based, can expect to see an increasing number of people with AIDS. It is important that these dietitians have access to and be able to build upon the knowledge and experience of those dietitians who have been treating PWAs. As more information is gathered nationwide, it is important that the dietitians in this state have access to it. All dietitians working with PWAs will need to know about research findings that relate to nutrition, about drugs that are being used and their possible side effects, and about alternative therapies or home remedies being promoted.

Physicians appear to be aware of the role of nutrition in the care of very sick, hospitalized PWAs. It appears, however, that few physicians consider calling for nutritional consultation for their patients before they reach this stage of their illness. Physicians are often the only person seeing the PWA while that PWA is at home. Many are not knowledgeable enough to discuss an appropriate diet with his/her patient or to refer the PWA to a dietitian – particularly when an opportunistic infection appears to be interfering with diet. Physicians need to know what appropriate nutrition and food resources are available for their patients.

Caregivers who are cooking for PWAs generally have little or no training in nutrition. These caregivers may be Chicken Soup Brigade volunteers, friends, family, or chore workers. Many feel that cooking is the one thing that they can do for the PWA, but they don't know what to prepare that will digest well, be appealing and taste good.

## Current Programs

### 1. Meal preparation and food service

Meals and food services available to PWAs are primarily provided by volunteers through the Chicken Soup Brigade (CSB). In 1988, the CSB provided 300 meals per week, serving approximately 140 people during the year. All meal preparation is done by volunteers either in their home or in the client's home. In some instances the PWA pays for the food, and sometimes the volunteer provides it. Sometimes food is donated directly to CSB. Fresh foods and foods that need to be frozen cannot be stored for any length of time at Chicken Soup because of limited refrigerator space. The CSB provides a bag of groceries to about 40 PWAs every two weeks. These groceries come from donations. The CSB has $20,000 available for 1987-88; $30,000 per year for the next two years will come from HRSA

to purchase 6,500 meals for PWAs. The CSB is looking into preparing meals themselves or purchasing meals from existing food programs. To date, no program has been put in place.

At the time that PWAs apply for welfare or Medicaid from the Department of Social and Health Services, they can also apply for food stamps. Some PWAs are eligible for food stamps; however, the amount they are generally eligible for is quite small. There are no data on how many PWAs use the Seattle food banks, but food bankers have suggested that PWAs don't seem to be able to eat much of the food they are able to distribute. They are not sure what kinds of foods to provide to PWAs and would like some direction.

There are several meal programs in the community – the majority for seniors or children. The biggest home-delivered meal program in the county is the Meals on Wheels program, run by Senior Services and set up for those over 60 years of age. Because of the age requirements, few PWAs are eligible for this program. Those who are eligible can purchase these meals. However, when a group of PWAs taste-tested the meals, they reported that the texture made them hard to swallow.

Other community meal programs offer hot meals at a certain location, but have no arrangements for home delivery or frozen food services. Many of these programs are targeted towards specific populations (elderly, ethnic groups, recovering alcoholics, etc.) and the meals are prepared for the specific dietary needs of those groups. PWAs who are not homebound can eat at some of the walk-in programs, but they may find that the food does not meet their needs or tastes. Some of the hospitals are now able to purchase frozen foods and make them available to their patients. The cost of these meals, however, is $2.50 - $4.00 per meal.

Some PWAs – with severe wasting syndrome or oral lesions – may need to rely on nutritional supplements as their only source of nutrition. Nutritional supplements, such as Ensure, can be purchased from drug stores, but are very expensive. Meals on Wheels can distribute Ensure and other supplements at a reduced fee, but only to those over 60 years of age. In some instances, hospitals can provide nutritional supplements, and sometimes cases are donated to the Chicken Soup Brigade. If a patient has a physician's prescription, they can use medical coupons to buy nutritional supplements. Food stamps can also be used to purchase nutritional supplements. Visiting Nurse Services and Pike Market Clinic have nutritional supplements available for purchase at the same price as Meals on Wheels: purchasing a case of Ensure through Visiting Nurse Services would cost $16.00 per case instead of $24.00.

**2. Nutritional Counseling**

The dietitians at Swedish Hospital have developed some nutrition guidelines for physicians and PWAs; however, they have not been printed or distributed yet. The ARIS project in San Francisco and Nutrition Services, a member of the national AIDS Nutrition Network (Department of Health and Human Services) have developed brochures and informational material on nutrition and AIDS.

The University of Washington has set up a nutritional information network that provides general nutrition information and makes referrals for questions they are unable to answer.

The John Bastyr College of Naturopathic Medicine has established a research project that includes nutritional counseling and assessment for PWAs and others with HIV infection. They will also be carefully evaluating various alternative treatment programs being used throughout the county to see which ones do or do not work for PWAs.

Individuals have set up programs to provide education on healthy lifestyles. Other organizations – purporting to cure AIDS – have set up practices selling advice on diets and alternative therapies.

**3. Training for dietitians, physicians and caregivers**

The Greater Seattle Dietetic Association has set up an informal network to advise dietitians throughout the area and the State if they have questions about AIDS patients. The Washington State Dietetic As-

sociation does not have a formal position paper on AIDS, but does expect to see one from the American Dietetic Association by the end of 1988.

The Red Cross offers a training course for caregivers, but ,at present, has very little information or advice to provide regarding nutrition. It has not had much luck finding people qualified to speak on nutrition for PWAs at their sessions.

## Issues, Problems, Service Gaps

**1. The primary need related to nutritional counseling and assessment is for individualized and group dietary assessment and consultation for PWAs who are not in the hospital.**

In a report on hospital charges prepared by the DSHS AIDS Surveillance Unit and the Seattle-King County Department of Public Health AIDS Surveillance Unit, a review of 165 cases revealed that these cases experienced 3.5 hospitalizations averaging 12.9 days per follow-up year after diagnosis. This would mean that on an average PWAs spent about 1.5 months of their follow-up after diagnosis in a hospital and the remaining 10.5 months in the community. In discussions with dietitians, they stated that a PWA could benefit from a dietary consultation at least once a month during those 10.5 months. Based on these assumptions, total dietary consultations per year are estimated as follows:

| | |
|---|---|
| 1988 | 5,934 |
| 1989 | 8,970 |
| 1990 | 12,730 |
| 1991 | 17,388 |
| 1992 | 22,046 |
| 1993 | 29,348 |

(About 50% of the counseling sessions could be group sessions; 50% would need to be individual sessions.) The estimate of initial assessments may be high if hospital dietitians do the assessments and work with outpatient dietitians to share information.

**2. Nutritional information**

Nutritional information is needed for PWAs, caregivers and physicians. Brochures should be developed that address:

a. The importance of nutrition in overall health.

b. Dietary guidelines for healthy diets.

c. The effects of drugs and specific infections on chemical balance – what to eat when you have certain opportunistic infections or are taking specific drugs and how these foods might affect you.

d. Evaluation and assessment of alternative therapies and their affect on nutrition.

e. How to encourage appetites and overall eating.

f. Recipes and meal plans that work when a person has AIDS.

g. List of available meal programs and resources for food or nutritional information.

Individuals who are HIV seropositive should be given general guidelines for good diet at the time they are told they are HIV-seropositive. PWAs should receive easy-to-read nutritional information at the time that they are diagnosed. Information for care givers should be made available either through the Red Cross, CSB, other support programs or the PWAs directly. The Washington State Medical Society, the Washington State Nurses Association, and the Washington State Dietetic Association should be involved in providing information to their members. The PWA newsletter can be used to provide information to PWAs.

To ensure that the material provided to PWAs is accurate and appropriate, all nutritional guides should be reviewed and given a stamp of approval by the medical society and/or the dietetic association before they are disseminated for public use.

If one brochure were handed out to each newly diagnosed PWA and one to their care givers, about 1000 should be printed in 1988, 1200 in 1989, 1500 in 1990, 1900 in 1991, 2200 in 1992, and 2700 in 1993.

**3. Help with Shopping, Food Preparation and Feeding**

In an effort to estimate how many meals would need to be prepared for PWAs in the year 1990, the following assumptions were made:

a. 45% of the PWA population requests services from Chicken Soup Brigade. This is likely to increase to 55% over the next 5 years.

b. 60% of the PWA population CSB serves needs meals prepared. This is likely to increase to 70% the next 5 years.

c. PWAs need 3 meals per week for about 5 months.

d. PWAs, pre- and post-hospitalization, need 11 more meals per week.

PWAs average 1.3 hospitalizations per year so 2.6 weeks/yr need 14 meals per week.

Based on these assumptions, the total meals needed per day would be as follows:

| | |
|---|---|
| 1988 | 35 |
| 1989 | 57 |
| 1990 | 87 |
| 1991 | 128 |
| 1992 | 173 |
| 1993 | 247 |

Based on the fact that CSB is not serving all PWAs and that members of CSB feel that three meals per week is a minimum number, these estimates should only be accepted as the minimum number of meals needed. A hot delivered meal program established in San Francisco is presently providing meals to about 250 PWAs per day. Their philosophy is to provide meals to any diagnosed PWA for as long as they want to be part of the program. They believe that helping a PWA get well balanced meals all the way through their illness will help keep them healthier and allow them to be active or work longer.

**4. Nutritional Supplements**

At this time there is no specific method for determining the amount of nutritional supplements needed. Case managers estimate that as many as 50% of PWAs use nutritional supplements at some time in their illness with a majority of those who have PCP or wasting syndrome using supplements for the last 2-3 months of their life. Dietitians confirm that about 50% of those with wasting syndrome could

use nutritional supplements. However they indicate that the time someone may use supplements could range from one week to 2 years.

In an effort to determine the number of cases of nutritional supplements that need to be made available for PWAs who cannot afford to purchase them on their own, the following assumptions were made.

a. 20% of PWAs have a diagnosis of wasting at some point in their disease (based on appropriate level of care study data which indicated 15 or 20% of PWAs had wasting during the course of their illness.)

b. 50% of those with wasting could use nutritional supplements.

c. 30% of PWAs have no third party reimbursement and could not afford to pay for nutritional supplements. (Based on "Hospital Charges for PWAs in Washington State")

d. Nutritional supplements would be needed on an average for 2 months by each PWA (60 days @ 5 cans per day = 300 cans).

e. Each case has 24 cans.

Based on these assumptions, nutritional supplements for PWAs would be needed in the following amounts:

| | |
|---|---|
| 1988 | 16 |
| 1989 | 24 |
| 1990 | 34 |
| 1991 | 47 |
| 1992 | 60 |
| 1993 | 87 |

In discussions with case managers at Swedish and Harborview, they indicated that about 15 to 20 cases of nutritional supplements were needed each month during the last quarter of 1987 and the first quarter of 1988. This estimate appears to be very close to the amount projected in the above method.

**5. Education and training**

The following are needed to assist in education and training

a. Conferences or presentations on nutrition and the AIDS patient geared for dietitians, physicians and other health care providers.

b. Speakers who are trained and knowledgeable in the area of nutrition for the AIDS patient.

c. A network of dietitians that are following the changes in treatment and the effect of new treatment on nutrition.

d. Physicians and dietitians working as a team to care for PWAs.

e. Training sessions for CSB volunteers, chore workers and other caregivers on nutrition.

# F. Housing

## Background Information

The need for affordable housing for persons with AIDS in Seattle-King County was early identified as a need, and considerable planning and development has occurred to address this need. Much of the analysis has been coordinated by the Housing Coordinator at the Northwest AIDS Foundation (this position paid for by grant funds through a subcontract with the Health Department). The subject also received special treatment in a study of housing needs in King County completed by the King County Department of Housing and Economic Development. The results of this plan are contained in a report published in December 1987 called, Bridging the Housing Gap.

One conclusion of the planning activities is that, to the extent possible, multiple types of housing arrangements should be available for low-income persons with AIDS. This differs from the strategy in some cities of channeling all persons with AIDS in need of housing to group homes or to housing projects. The options which are available reflect this underlying principle (see next section on Current Programs).

Twenty-four percent of the people living with AIDS in Seattle are in some type of subsidized housing. As far as it is possible to ascertain, this is among the highest percentages in the United States. San Francisco, for instance, with over 2,000 cases has fewer than 100 subsidized units available. It should be the aim of programs in Seattle-King County to continue to make housing available for the 24% of the people living with AIDS who will need it.

The magnitude of this need for housing assistance is due to the low income of many PWAs. 70% of all Northwest AIDS Foundation clients are very low income, living on less than $400 per month. Of the 93 people who received housing assistance over a three month period this summer, 95% were spending 50% or more if their income on housing.

## Current Programs

**Emergency Housing:** In late 1986 the NWAF requested and received from the City of Seattle (Department of Human Resources) funding for four emergency/transitional rooms at the Morrison Hotel in downtown Seattle. In 1987 that number was reduced to three due to limited numbers of requests. The location of the Morrison -- adjacent to the bus tunnel digging project on Third Avenue -- was not ideal for persons with AIDS, and in September, 1987, the three rooms were changed to three studio apartments at the Cambridge Apartments, adjacent to the convention center. This building is owned by the Seattle Housing Authority. In 1988, three additional apartments at the Cambridge have been added and there are plans to increase this to twelve by the end of 1989. There are currently four on the waiting list for the Cambridge.

**Permanent Housing:** The Seattle Housing Authority, with approval from HUD, has made available 20 section 8 certificates which can be used to subsidize rent in approved buildings, including the Cambridge Apartments. There are currently 44 eligible PWAs on the waiting list for Section 8 vouchers. Also, individuals can apply for subsidized SHA apartments just as other disabled and elderly low income persons can. From April to August 1988, 46 clients applied for this conventional housing program of the SHA.

Other options include the following:

- several area churches have established subsidies -- some are a set amount each month, others are in support of housing for one individual's housing needs -- and church subsidies and PWA needs are matched by the NWAF Housing Coordinator (these subsidies have helped 41 clients since January 1988);
- rooms and apartments are available as they become available at the Vincent House, a subsidized facility for the elderly and disabled run by the Sisters of Providence, and four units at the Payne Apartments, run by the Plymouth Housing Group (currently filled, with 3 on the waiting list);
- a group home which can house six PWAs was recently opened by University Unitarian Church (currently serving 6 with 3 on the waiting list);

Under all options there is strong involvement of the Housing Coordinator and Resident Advocate at the NWAF.

By the end of 1988, all programs together will account for at least 67 units of subsidized housing for PWAs. In addition, there is continued interest from other groups about developing other housing options. One of particular interest would provide housing for PWAs who are also in recovery from drug and/or alcohol use.

## Issues, Problems, Service Gaps

1. Keeping up with demand for affordable housing for low income PWAs in Seattle-King County will require ongoing attention and resources. At a minimum, these actions will be needed:
   - continue to support Housing Coordinator and Resident Advocate at NWAF to develop options including those below and promoting continued involvement of churches;
   - ask City of Seattle to continue providing emergency/transitional housing and increase rooms as need requires;
   - ask Seattle Housing Authority to increase numbers of vouchers available to PWAs;
   - ask King County Housing Authority to develop housing options in the County;
2. Special attention is needed to develop housing for low income PWAs in King County outside of Seattle. The King County Housing Authority should be approached regarding development of housing options in the County.
3. Housing for special populations with HIV will be needed. These include women and children, substance using individuals and possibly those with dementia (though it is not clear whether persons with dementia might not need more care than could be provided in the independent housing options discussed here).

## G. Counseling/Emotional Support

**Among the community comments received during review of this Plan was an interest in seeing some discussion of the need for counseling/emotional support services for PWAs and for care providers. Such services have always been recognized as an important component in the continuum of care in Seattle-King County, and the issues and gaps in service should be identified in this Plan. As with other Plan sections, a community group concerned about this area needs to be convened to help with the needs assessment, and there is not time to do this and meet the current deadline. The Health Department is committed to coordinating the development of this section over the next several months for inclusion in the next edition of the Plan. The following paragraphs intoduce the topic and provide a place for the later material to be inserted.**

Counseling and emotional support for PWAs, their families and friends, and for persons who are HIV positive, is an essential component of the continuum of care. These services can be provided by both professionals and trained volunteers.

In addition to those directly affected by HIV infection and their families and friends, care providers need to have available supportive services to assist them in dealing with the emotional impact of working in this area. Programs aimed at avoiding burn out among committed providers must be developed.

Among the groups which have been activew in providing counseling/emotional support for the PWAs and others including care providers have been Seattle Counseling Services for Sexual Minorities, Shanti, Seattle AIDS Support Group, the Red Cross, and Stonewall Recovery Services.

# X. Research Related to AIDS and HIV Infection

## Background Information

If a general definition of research, such as the "systematic inquiry or investigation into a subject" (**The American College Encyclopedic Dictionary**) is used, it is immediately clear that numerous areas of research are relevant for the planning and implementation of AIDS-related prevention and educational programs, as well as for the provision of social and medical services. Several examples, which support the concept that social science and biomedical research is central to all of these efforts, follow.

The counting and description of the affected populations, known to some as surveillance, which has been one of the activities of epidemiologists from the state and King County for several years and forms the basis for much of King County's AIDS planning, is an example of biomedical (epidemiology) and/or social science (sociology) research. If done systematically, the use and evaluation of different strategies to inform white homosexual men and people of color about AIDS, is an example of a type of educational research. Investigating whether one-on-one counseling or group counseling is more effective at inducing behavioral changes in intravenous drug users would be research if it was done in a purposeful fashion. Research linked to the provision of medical services, such as determinants of the costs of care, is called health services research. Thus, many AIDS-related research efforts are not easily separated from other parts of King County's Five Year Plan, although such activities may fall under other headings, such as surveillance, intervention, outreach, planning, evaluation, etc.

Another major area of research related to AIDS is that of biomedical research, the area that many persons assume comprises most of AIDS research. Biomedical research can be broadly categorized into basic science (i.e. laboratory-based) and clinical (i.e. patient-oriented) research. For example, the observation that zidovudine (the official name for the antiviral drug known more commonly as AZT) inhibits the growth of HIV in a test-tube is a basic science observation, whereas a clinical research study showed that AIDS patients taking AZT were less likely to die than AIDS patients not taking it. Obviously, this particular clinical research outcome has had significant health policy, financial, and medical service delivery implications.

Clinical research may involve hospitalized patients or outpatients, and requires clinical facilities (inpatient beds and/or outpatient clinics), as well as biostatistical and laboratory facilities. For example, in one ongoing study of AZT at Harborview/University of Washington, blood specimens are sent to a total of five different laboratories in King County for study-related analyses. In fast-moving areas of medicine such as AIDS, new treatments may be available only through clinical research studies, and access to such treatments is (understandably) of tremendous importance to affected persons. Even after a treatment becomes available for use outside of studies, clinical research on that agent continues to evaluate such questions as new dosage schedules, different drug combinations or use of the drug in other patient populations.

Much of the initial clinical research on AIDS treatment was directed at patients with overt AIDS. The most notable success has been the development of AZT. Whether this drug will delay or prevent the development of AIDS in persons with early (asymptomatic) HIV infection is currently being studied. If AZT or other new antiviral drugs do prevent development of AIDS, then many more high risk persons will seek testing to see if they should be treated. As the number of patients who seek testing, counseling, medical follow-up, and antiviral treatment for HIV infection increases, existing facilities in King County will not be able to accommodate them unless future plans recognize this issue.

Traditionally, biomedical research has been conducted mainly at academic institutions, although some pharmaceutical companies and more recently biotechnology companies, have also performed and supported research efforts. Funding for most university based biomedical research has been primarily from the federal government through the National Institutes of Health (NIH) and to a lesser extent

through other federal agencies (e.g. Centers for Disease Control) and private foundations (e.g. American Foundation for AIDS Research). In some states, such as California, significant state and local funding has also been available for AIDS research. The potential for community-based organizations and private practitioners to perform AIDS-related biomedical research has also recently been recognized by both the federal government and private foundations, although is not yet a significant factor in King County.

## Current Programs

As indicated above, research efforts are an integral part of multiple programs which have primary goals sounding very different than pure research ones. This makes a complete listing of ongoing AIDS research in King County very difficult. However, research projects related to HIV infection and AIDS are currently being performed by a variety of organizations in King County, including but not limited to: University of Washington, Harborview Medical Center, Seattle-King County Department of Public Health, Fred Hutchinson Cancer Research Center, Puget Sound Blood Bank, Children's Orthopedic Hospital, physicians affiliated with Swedish Hospital Medical Center, John Bastyr College of Naturopathy, and private companies, including Genetic Systems Corporation, Oncogen, and Immunex.

One example of the scope of ongoing research is illustrated by a listing of disciplines involved in AIDS research at the University of Washington (UW) (Appendix A). In some projects, research is linked to training of health care providers, or combines clinical care or social services and research, but other are fundamentally research endeavors. Faculty at UW have been successful to date at obtaining federal grant support for many AIDS-related projects, although the creation of new programs and their growth have created critical space problems for many projects. Two of the highest profile AIDS projects at UW include the AIDS Clinical Trials Unit, which conducts treatment research (Appendix B) and the AIDS Vaccine Development project, which is conducting one of the first human trials of a candidate HIV vaccine.

In 1988, UW was awarded a five year National Institutes of Health (NIH) grant to establish a "Center for AIDS Research"(CFAR). In order to qualify to apply for one of these awards, institutions had to have already been awarded a certain amount of NIH-funded AIDS-related awards. The previous award figures for UW were $3 million (direct costs) from the National Institute of Allergy and Infectious Diseases (NIAID) and $6 million in other NIH supported AIDS research. Ninety-four different projects which have been funded or for which funding has been sought were described in the CFAR grant proposal. (The summaries of these projects are available for review by interested persons, but have not been included in this report.) The CFAR grant will provide some funding for facilities, although the award ($842,000 direct costs for year one) was substantially less than the requested funding. The CFAR project involves over 75 faculty. The abstracts for the UW CFAR and its six core components (immunology, retrovirology, clinical research, primate research, biostatistics/epidemiology, and administration) are attached (Appendix C).

## Issues, Problems, Gaps

1. Adequate space and funding for facilities in which to house the various research programs has been and will continue to be a significant issue. The extent to which these programs or personnel supported by these programs provide services that are useful and desired by King County residents (e.g. access to experimental drugs at no cost, expertise for local educational programs, grant funding for services that local dollars would otherwise be supporting) makes the lack of facilities a relevant issue for a King County AIDS plan.

For example, in 1988 the UW AIDS Clinical Trials Unit at Harborview had 4000 patient visits by the 250 persons enrolled in ongoing trials. One of those trials, a study of AZT in persons with asymptomatic HIV infection, provides the drug for 2/3's of the enrollees in that trial for at least 3 years. Although not yet demonstrated, many investigators suspect that the benefits of early AZT treatment will be substantiated by this trial. Nationwide, 3300 persons will be enrolled in this study, although locally the unit only has space and personnel for about 120 persons out of the estimated 10,000-15,000 HIV-seropositive persons in King County. Given the cost of AZT ($8,000/year for drug alone), it may be cost effective for the county to provide facilities to expand this unit and permit greater access to this therapy.

Currently, Harborview/University of Washington AIDS-related clinical research, service delivery and training programs are scattered in several locations in Seattle. Planning to permit co-location of projects for an "intermediate" time frame (while Harborview's clinical facilities are renovated and a new clinic building is constructed) is ongoing. Ultimately, the AIDS programs, institution, and King County residents served by the programs will benefit by re-locating these programs back at Harborview. This plan would clearly impact on King County planning for future expenditures.

In addition to a lack of clinical facilities, there is a lack of sufficient specialized laboratory facilities for AIDS care and research. Work with HIV requires a specialized, ventilated (P-3) level laboratory. Because of the hazards involved in working with this virus, laboratory facilities must not be crowded and persons cannot be stressed or overworked, or mistakes will be made. A few laboratory workers have already been infected with HIV in other laboratories in the U.S. Presently, the existing retrovirology laboratory is barely able to accommodate the research specimens. Few resources are available for pediatric work, where sophisticated laboratory studies, including HIV cultures, are needed to identify infected neonates. No monitoring for persons on therapy other than in research trials or for patients throughout the County is available. This is in contrast to California, which has set up a regional AIDS isolation laboratory at U.C. Davis for monitoring patients throughout their state who are on antiviral chemotherapy.

2. A related issue to #1 is that of equitable access to research programs for all HIV-infected populations in all parts of King County.

A 1988 grant application by investigators at Children's Orthopedic Hospital to initiate pediatric AIDS treatment research studies was not funded, primarily because of the small number of infected children in this area. For the short-term, access to pediatric studies will be possible by special arrangement with the already operational UW AIDS Clinical Trials Unit, but financial constraints will likely preclude this arrangement within a year.

Currently, research programs are focused in central Seattle, and available funding will not permit expansion to other parts of the county. The current programs do not exclude persons not residing in Seattle, but it is markedly less convenient for such persons to participate.

3. It should be noted, too, that Seattle will continue to draw patients from surrounding states and British Columbia if Seattle provides the only oppportunity to participate in clinical trials. This, of course, further stresses the Seattle programs.

4. Is the current focus of AIDS research projects ideal for the goals of King County? Is the mix of social science and biomedical studies optimum? Are all the questions important to King County being addressed? Since the County provides no direct funding for many of these projects, it obviously can not control the direction of the research conducted. There may be areas of high priority, where the County might wish to have formal input into study implementation.

For example, given the worrisome trends about increasing sexually transmitted disease rates in minorities, additional studies identifying the most effective educational strategies for people of color may be warranted. Certain health care delivery issues, such as adequacy of Medicaid reimbursement

for local providers, may have significiant impact on access to medical care for King County residents or the financial solvency of area institutions. Another example concerns intravenous drug users. Given the relatively low prevalence of HIV infection in intravenous drug users in this area relative to many other U.S. cities, it might be important to identify the **most** effective strategies to affect behavioral changes (drug use and sexual activity) in the population at risk **as soon as possible**, in order to prevent a much larger AIDS problem in King County in the future. These are only three examples of research questions of potential importance to the County.

4. Is community-based medical research a high enough priority in King County to provide funding or facilities for?

## Appendix A — Disciplines at UW Involved in AIDS Research

Adolescent Medicine
Alcohol & Drug Abuse Institute
Anesthesiology
Animal Medicine
Anthropology
Biostatistics
Dentistry
Epidemiology
Health Services
Immunology
Infectious Diseases
Laboratory Medicine
Medicine
Neurology
Nursing
Oral Medicine
Pathology
Pediatrics-
Pharmacology
Psychiatry
Psychology
Public Health
Radiology
Rheumatology
Social Work
Sociology
Virology

# Appendix B • UW AIDS Clinical Trials Unit Update (1/89)

For the first two years of the University of Washington AIDS Clinical Trials Unit operation, we have focused our efforts on antiviral studies. Other clinics within the nationwide treatment research organization have conducted studies of opportunistic infection (OI) treatments and immunomodulators. As a result of expansion in our unit, we plan to initiate a few studies of OI treatment and/or prophylaxis in the near future. Drs. Mac Hooten and Jan Agosti will be the lead physicians for these studies. The first OI study (planned to start in mid-winter) will be of primary **Pneumocystis carinii** pneumonia (PCP) prophylaxis. It will investigate several prophylactic regimens for PCP in patients meeting the FDA labeling indications for AZT, but who have not had PCP or toxoplasmosis. Further details about our OI efforts will be forthcoming.

The phone number for study referrals (Michi Thacker, Study Coordinator or George Bergerson, Clinic Assistant) is 223-3184. Our street address is 1120 Cherry Street, Suite 400. Our mailing address is:

Harborview Medical Center
325 Ninth Avenue, ZA-00
Seattle, WA 98104

Currently we have twelve studies underway, and are actively seeking patients for the following studies:

1) **AZT/Acyclovir for Mild ARC**: Antiviral study of combination therapy of AZT and Acyclovir vs. AZT alone for AIDS-related complex. Treatment duration is 3 months. Specific entry requirements include the presence of some constitutional symptom(s), T4 counts between 200-500/$mm^3$, positive p24 antigen; exclusions include persistent oral candidiasis, prior AZT therapy.

2) **TNF-Gamma IFN for ARC**: Phase I/II study of tumor necrosis factor, gamma interferon, or the combination for ARC. Treatment is IM 3 times per week for 16 weeks with potential for extension. Entry requirements include T4 /$mm^3$; exclusions include history of varicella zoster, ongoing therapy with aspirin, anti-inflammatory agents, steroids, antihistamines or anti-retroviral therapy.

3) **Foscarnet for HIV Infection/ARC/AIDS**: Antiviral trial of intravenous foscarnet therapy TID for 4 weeks (with potential for extension of Rx). Patients must be p24 antigen positive with T4 /$mm^3$. Requires a 2 day inpatient hospitalization followed by outpatient (home) Rx.

4) **AZT vs. Placebo for HIV Asymptomatic's**: Multicenter trial of 2 doses of AZT vs. placebo. Treatment period is a minimum of 3 years. Subjects may have asymptomatic lymphadenopathy. Patients can have T4 counts of any value.

5) **AZT vs. Placebo for Early ARC**: Multicenter trial of AZT vs. placebo; treatment is for a minimum of 104 weeks. T4 counts must be 200-800/$mm^3$.

6) **AZT for AIDS Dementia Complex**: Multicenter trial of AZT (200 mg 5X day) for 24 weeks for persons with typical signs and symptoms of neurological impairment attributed to HIV. Entry criteria include T4 ^/$mm^3$ or history of an AIDS-defining opportunistic infection.

7) **AZT in Liver Disease**: Two day pharmacokinetic study in patients with HIV infection and mild, moderate or severe liver dysfunction, to help determine appropriate dosing for these patients.

8) **AZT versus AZT/Acyclovir for AIDS**: Antiviral study of 2 different doses of AZT alone versus those doses plus acyclovir. Treatment duration is two years. Entry requirements are PCP or AIDS-related OI; exclusions include need for ongoing systemic antimicrobial Rx other than PCP prophylaxis or previous AZT for more than 8 weeks.

9) **AZT vs. Placebo for Hemophiliacs**: Multicenter trial in conjunction with hemophilia centers and the National Hemophilia Foundation. Entry criteria include asymptomatic HIV infection and T4 /$mm^3$. Drug will be taken 5 times/day. Treatment duration is 2 years. Screening for this study is via the Puget Sound Blood Center at 292-1874.

**Screening tests, study medication, laboratory and clinical monitoring are free. If you would like to refer a patient or obtain more information, please call Michi Thacker or George Bergerson at 223-3184.**

PRINCIPAL INVESTIGATOR/PROGRAM DIRECTOR: _____

DESCRIPTION: State the application's broad, long-term objectives and specific aims, making reference to the health relatedness of the project. Describe concisely the experimental design and methods for achieving these goals. Avoid summaries of past accomplishments and the use of the first person. This abstract is meant to serve as a succinct and accurate description of the proposed work when separated from the application. **DO NOT EXCEED THE SPACE PROVIDED.**

**The proposed UW CFAR is organized around 6 core units: Administration (including information transfer/publications and research training); clinical and molecular retrovirology; immunology; clinical research; biostatistics and epidemiology (including International AIDS Research and AIDS Registry); and non-human primate research. Two additional core units, behavioral sciences research and radiological imaging research, are envisioned via separate funding in future years. Over 75 faculty staff investigators of the proposed CFAR participate in active or pending research grants directly related to AIDS, HIV, or SIV and many of these also have other active grants in closely related fields such as non-primate retrovirology, molecular/cellular immunology, and other STDs. Ten distinct AIDS related research themes have been identified, many involving parallel research in humans and non-human primates. The proposed CFAR would help coordinate this research to ensure efficient use of primates in research most relevant to human infection. Six active and two pending institutional post-doctoral research or clinical training grants at the UW are AIDS related. The process of planning this proposal has helped to coordinate the new allocations of 7450 sq. ft. of lab space to basic research on HIV and SIV. The CFAR would fund alteration, renovation, and equipping of a portion of these labs on the UW campus and at Fred Hutchinson Cancer Research Center. Planning for relocation of the HMC AIDS Clinic and the NIAID ACTU is already funded and underway. The CFAR would fund creation and co-location of a CFAR Clinical Research unit, including clinical and epidemiologic research trainees at the same site as the AIDS clinic and ACTU.**

KEY PERSONNEL ENGAGED ON PROJECT

| NAME, DEGREE(S), SSN | POSITION TITLE AND ROLE IN PROJECT | DEPARTMENT AND ORGANIZATION |
|---|---|---|
| King K. Holmes, M.D.,Ph.D. 353-28-0854 | Professor, P.I. | Medicine, Micro, Immunology |
| Doug Bowden, M.D.308-38-2549 | Professor,Dir.,Primate Core | Psychiatry & Behav. Sciences |
| Lawrence Corey,M.D. 363-48-4882 | Professor, Dir.,Retrovirology Core | Medicine, Micro, Immunology |
| Philip D. Greenberg, M.D. 134-34-3861 | Asso. Prof., Director, Immunology Core | Medicine, Micro, Immunology |
| H. Hunter Handsfield, M.D. 056-34-4400 | Asso. Prof.,Director, Clinical Core | Medicine |
| David W. Johnson, M.D. 531-24-1240 | Professor, Director, Administrative Core | Medicine |
| Ann Collier,M.D.,218-50-6445 | Asst.Prof;Asso Dir, Clinical | Medicine |
| Tom Fleming, Ph.D.,474-52-4019 | Prof.,Asso.Dir.,EPI/BIO Core | Biostatistics |
| Laura Koutsky,Ph.D.534-56-4636 | Inst.,Asso.Dir.,EPI/BIO Core | Medicine |
| Joan Kreiss,M.D.,M.S.P.H. 156-42-5269 | Asst. Prof., Asso. Dir., Adm.Core & EPI/BIO Core | Medicine & Epidemiology |
| Maxine Linial,Ph.D.133-34-0805 | Asso.Prof., Asso. Dir,Retrov. | Microbiology |
| Walter E.Stamm,M.D.519-50-7381 | Prof.,Asso.Dir.,Admin.Core | Medicine, Micro, Immunology |

15. CENTER INTRODUCTION

A. Center Objectives

1. To coordinate, stimulate, and support collaborative interdisciplinary AIDS-related research and research training at the University of Washington and Affiliated Institutions. Ten program areas of interdisciplinary research are described below.

2. To facilitate and coordinate access of investigators to patients with AIDS and other HIV infections

3. To facilitate research on SIV infection in nonhuman primates, and to closely coordinate such research with concurrent research on HIV infection, to ensure that primate models of retroviral infection are used efficiently in research which is highly relevant to human disease

4. To provide initial support for young investigators or those new to the field of AIDS-related research; and to foster the application of new knowledge in related fields to the study of problems related to AIDS

B. CFAR Planning Committee

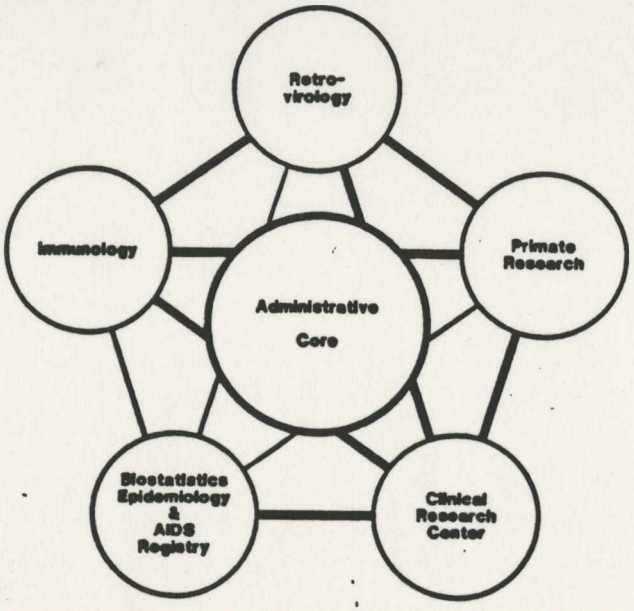
Dr. Michael Whitcomb, Dean of the School of Medicine, corresponded with the Dean of other Schools in the Health Sciences, and with all Department Chairs in Medicine inviting each to participate in development of this CFAR proposal. Dr. Holmes subsequently communicated with each respondent, and formed a Planning Committee, consisting of the following:

-Douglas Bowden, Ph.D.- Director, Regional Primate Center-Donald Calsyn, Ph.D. - Acting Director, Drug Dependeney Treatment Program, VAMC, Assistant Professor of Psychiatry
-Lawrence Corey, M.D. - Professor, Laboratory Medicine; Microbiology and Immunology
-Timothy DeRouen, Ph.D.- Professor of Biostatistics and Chairman of Public Health, School of Dentistry
-Hunter Handsfield, M.D.- Professor of Medicine, Chief, Sexually Transmitted Disease Division, Seattle-King County Department of Public Health
-Maxine Linial, Ph.D. - Research Associate Professor of Microbiology; Division of Basic Sciences, Fred Hutchinson Cancer Research Center
-James McDougall, Ph.D - Professor of Pathology; Director, Experimental Pathology, Fred Hutchinson Cancer Research Center
-Patricia Wahl, Ph.D. - Professor of Biostatistics and Associate Dean, School of Public Health
-Noel Weiss, M.D., Ph.D. - Professor and Chairman, Epidemiology
-Christopher Wilson, M.D. - Professor of Pediatrics
-Robert Wood, M.D. - Associate Professor of Medicine; Director Seattle-King County AIDS Prevention Project

The Planning Committee initially met to discuss options and opportunities for extending the effectiveness of AIDS-related research at the University through organized interdisciplinary coordination and development of shared resources; and to identify potential staff investigators. A mailing was then sent to potential CFAR staff investigators, inquiring about AIDS-related research, interest in participating in the CFAR, and about needs that could be met through a Center. Core directors were identified by Dr. Holmes in consultation with appropriate Chairs and Deans. The final meeting of the Planning Committee was held to review the Administrative Structure and organization of the proposed CFAR and advise Dr. Holmes on total budget and budget priorities.

The proposed Center for AIDS Research (CFAR) has been organized around six core units: Administrative (including information/publication and research training sections); Retrovirology; Immunology; Biostatistics and Epidemiology (including an AIDS Registry); Clinical Research; and Nonhuman Primate Research. Two additional Core Units envisioned for future years include Behavioral Sciences Research and Radiological Imaging Research. These core units will serve the needs of investigators throughout the University, and will serve as the nucleus for program planning for AIDS related research within each of these major research areas. Interaction between these

six core units is depicted in the accompanying figure, in which frequent and extensive interdisciplinary collaborations are indicated by the heavier conecting lines.




The School of Medicine has recently allocated approximately 5200 square feet of new laboratory space and has reallocated 1650 square feet of existing laboratory space to AIDS-related research, in support of the proposed CFAR. The CFAR would fund renovation of this latter reallocated space, as well as development of a high level containment 800 square foot laboratory for work with HIV at the Fred Hutchinson Cancer Research Center, and would provide equipment for shared use by investigators from many disciplines in the new CFAR core research laboratory facilities.

C. Center Investigators

Over 75 investigators at the University of Washington have active or pending research which is directly concerned with AIDS, HIV, or SIV, will participate as staff investigators in the proposed CFAR, and are listed in Table 7. Many other investigators at this institution are involved in relevant research indirectly related to AIDS, and could participate in and benefit from a CFAR at this institution. Brief descriptions of the Background of the Core Directors and Associate Directors follow:

## BACKGROUND OF CORE DIRECTORS

King K. Holmes, M.D., Ph.D. (Professor and Vice Chairman of Medicine/Adjunct Professor of Epidemiology, Microbiology and Immunology)

Dr. Holmes' role as Center Director will be facilitated by adjunct faculty appointments in Microbiology and Immunology and in Epidemiology. He has experience as Affiliate Investigator in the Primate Center from 1976 through 1987, and in collaborative research with investigators at the Fred Hutchinson Cancer Research Center. His research administrative experience includes serving as P.I. on interdisciplinary multi-institutional NICHD Consortium Grant for research on HIV infection in Africa. Other relevant administrative experience includes 5 years as Vice Chairman of the Department of Medicine and Chief of Medicine at Harborview Medical

DESCRIPTION: State the application's broad, long-term objectives and specific aims, making reference to the health relatedness of the project. Describe concisely the experimental design and methods for achieving these goals. Avoid summaries of past accomplishments and the use of the first person. This abstract is meant to serve as a succinct and accurate description of the proposed work when separated from the application. DO NOT EXCEED THE SPACE PROVIDED.

The rapid proliferation of laboratory, clinical and epidemiologic research on AIDS and basic and applied research on HIV and SIV, has created not only a need for laboratory and clinical facilities, equipment, and personnel, but also a need for coordinated planning of research programs and resource development, prioritization of need, sharing of resources, rapid information transfer, and nurturing of trainees in a complex and rapidly changing environment. The specific objectives of the Administrative Core of the proposed University of Washington CFAR are to assist the Center Directors and Scientific Core Directors in achieving the 4 general goals of the Center, to coordinate external relationships, and to address legal and ethical issues surrounding Center activities. The CFAR will have 3 components. The Central Operations Office will be responsible for financial analysis and control, and operations management. The Information and Publications Unit will produce a CFAR newsletter, introduce the CD-ROM bibliographic search system and train investigators and trainees in using the system, provide computer networking for document and data transfer between Cores and staff investigators via the John Locke Computer System, provide computer graphics, word processing, and editorial assistance, and coordinate the educational activities of the Center, including the AIDS Core Curriculum, the AIDS Clinical and Research Seminars, AIDS/Retrovirology Journal Club, a Speakers/Consultants Program, and an annual Center Research Retreat. The Research Training Coordination Unit will coordinate recruitment of trainees and allocation of resources such as office space and secretarial help to the trainees on six active AIDS-related training grants, and potentially large numbers of foreign trainees on two pending Fogarty Center Training Grants for AIDS Research. This Unit will also coordinate the Core Curriculum content of training with each trainee and preceptor, and will help with arranging visas, medical licensure, insurance, travel, and housing.

KEY PERSONNEL ENGAGED ON PROJECT

| NAME, DEGREE(S), SSN | POSITION TITLE AND ROLE IN PROJECT | DEPARTMENT AND ORGANIZATION |
|---|---|---|
| King Holmes, M.D.<br>SSN - 353-28-0854 | Center Director | U.W. Departments of Medicine, Microbiology & Immunology, Epidemiology |
| David Johnson, D.V.M, M.D.<br>SSN - 531-24-1240 | Director for Administration | University of Washington WAMI Program |
| Joan Kreiss, M.D., M.S.P.H.<br>SSN - 156-42-5269 | International Training Program Coordinator | U.W. Departments of Medicine and Epidemiology |
| Walter Stamm, M.D.<br>SSN - 519-50-7381 | Associate Director for Research Training | U.W. Departments of Medicine and Epidemiology |

CORE B: PRIMATE CENTER PRINCIPAL INVESTIGATOR/PROGRAM DIRECTOR: King K. Holmes, M.D., Ph.D.

DESCRIPTION: State the application's broad, long-term objectives and specific aims, making reference to the health relatedness of the project. Describe concisely the experimental design and methods for achieving these goals. Avoid summaries of past accomplishments and the use of the first person. This abstract is meant to serve as a succinct and accurate description of the proposed work when separated from the application. DO NOT EXCEED THE SPACE PROVIDED.

Much basic research on the biology and pathogenesis of viral disease depends upon access to suitable animal models. The best animal models of AIDS are the immunodeficiency syndromes produced in macaques by the Simian Immunodeficiency Viruses (SIV). The University of Washington is one of few biomedical institutions in the U.S. engaged in substantial AIDS research whose faculty have immediate access to a sizable primate research facility allowing work in the macaque models. Investigators at the Regional Primate Research Center (RPRC) at the University of Washington have established an SIV model in the Macaca nemestrina (SIV/Mne). Their SIV research is well funded (projected at $2.5 million in 1988-89), but not well integrated with other AIDS-related research at the University. SIV research in the areas of molecular virology, basic immunology, pathogenesis, pathology, and vaccine development will be fostered and integrated into the University's overall AIDS research program by several features of the Center for AIDS Research (CFAR).

The RPRC will designate a 1500 sq. ft. P-3 animal housing and laboratory area within its existing facility as the Primate Core of CFAR. The Primate Core will provide CFAR affiliates priority access to the animals and equipment necessary for conducting those aspects of SIV research that require contact with infectious animals, cell cultures, and reagents. In addition, the CFAR will renovate an area designated by the Department of Microbiology of the School of Medicine for virologic aspects of SIV research, where first priority will go to faculty who are affiliates of CFAR and are funded for SIV research. The Immunology Core of CFAR will purchase equipment, including a cell analyzer, which will be made available to CFAR affiliates working on immunological aspects of SIV (and HIV) in a facility in the Department of Immunology designated for such work. The Primate Core will provide CFAR affiliates with specimens from SIV/Mne-infected animals at all stages of infection and disease, and access to a panel of labeled monoclonal antibodies to leukocyte differentiation antigens, such as CD4, CD8, and CD18, for counting and sorting macaque lymphocytes. These reagents allow the use of an existing two-color fluorescence-activated cell sorter that will be available to CFAR affiliates.

KEY PERSONNEL ENGAGED ON PROJECT

| NAME, DEGREE(S), SSN | POSITION TITLE AND ROLE IN PROJECT | DEPARTMENT AND ORGANIZATION |
|---|---|---|
| Douglas M. Bowden, M.D.<br>309-38-2549 | Director, NonHuman Primate Research Core | University of Washington<br>Regional Primate Center<br>Department of Psychiatry and Behavioral Sciences |

DESCRIPTION: State the application's broad, long-term objectives and specific aims, making reference to the health relatedness of the projec Describe concisely the experimental design and methods for achieving these goals. Avoid summaries of past accomplishments and the us of the first person. This abstract is meant to serve as a succinct and accurate description of the proposed work when separated from th application. DO NOT EXCEED THE SPACE PROVIDED.

Recognition of the magnitude and consequences of the health problem posed by the AIDS and related viruses has resulted in a committed multidisciplinary effort by the scientific community to address and eventually solve the relevant issues. Since the immune response represents the major host defense to challenge by a virus, clinical and basic immunologists have become increasingly involved in this effort. Although several years ago only a small number of University of Washington immunologists were involved in AIDS-related research, the eight faculty members listed in this core are now independently funded for investigations into varied aspects of the immunobiology of AIDS, and other members of these and affiliated laboratories are involved in related and/or collaborative studies. This rapid increase in research efforts related to AIDS has identified and created many problems--the most outstanding of which have been: a shortage of space, equipment, and resources necessary both for performing the proposed studies and for initiating studies exploring new areas; a lack of central shared facilities to provide standard uniform reagents, to permit safe culture of both virus and potentially infected cells, and to promote interaction of investigators; and the absence of an administrative structure to organize a diversified program for the effective training of post-doctoral fellows and visiting scientists. Thus, it is the purpose of the core facility proposed in this project to provide resources, support, and staffing for a cohesive, integrated, collaborative program investigating the immunobiology of AIDS.

The specific goals of the Immunology Core will be to provide: (A) Centralized laboratory facilities adjacent to a human retrovirus P3 laboratory for studies of HIV immunobiology with capabilities of performing molecular, biochemical, and cellular analyses; (B) A core laboratory adjacent to a primate retrovirus P3 laboratory for studies of SIV immunobiology with facilities for performing molecular, biochemical and celluiar analyses; (C) A fluorescence-activated cell analyzer and sorter facility for analytic studies of antigen expression, cell cycle progression, signal transduction, and receptor expression and specificity, and for sorting and cloning selected cell subpopulations; (D) A hybridoma facility capable of cloning and maintaining antibody-producing lines and of producing and purifying monoclonal antibodies; (E) A bank for the storage of cell lines and tissues; (F) A facility for the analysis, preparation and purification of HIV- and SIV-specific peptides and cell proteins; (G) A quality-controlled media preparation and glassware washing-sterilization facility; (H) A centralized library to enhance information acquisition, with the capacity to perform computerized literature searches; (I) An organized program to promote sharing of expertise and collaborations between investigators currently performing or interested in developing AIDS-related research projects; and (J) A diversified centralized program in the immunobiology of AIDS and related disorders for the training of fellows and of visiting domestic and international scientists.

KEY PERSONNEL ENGAGED ON PROJECT

| NAME, DEGREE(S), SSN | POSITION TITLE AND ROLE IN PROJECT | DEPARTMENT AND ORGANIZATION |
|---|---|---|
| Philip D. Greenberg, M.D.<br>134-34-3861 | Head, Core Program in Immunobiology | University of Washington<br>Departments of Medicine a<br>Microbiology/Immunology |

PRINCIPAL INVESTIGATOR/PROGRAM DIRECTOR: King K. Holmes

**DESCRIPTION: State the application's broad, long-term objectives and specific aims, making reference to the health relatedness of the project. Describe concisely the experimental design and methods for achieving these goals. Avoid summaries of past accomplishments and the use of the first person. This abstract is meant to serve as a succinct and accurate description of the proposed work when separated from the application. DO NOT EXCEED THE SPACE PROVIDED.**

We propose to develop a clinical and molecular retrovirology core unit to provide virologic support to ongoing research on the epidemiologic, immunobiology, experimental pathogenesis, and basic molecular core virology of HIV and SIV at the University of Washington. The core would physically and functionally consist of three separate but interactive components.

The first consists of a P-3 laboratory, and a molecular virology laboratory, both to be constructed adjacent to a HIV immunology laboratory (directed by Dr. Greenberg) in the Health Sciences complex. The core P-3 laboratory would allow investigators and visiting scientists involved in biochemical, immunological and other HIV related work to work with live HIV and have access to purified virions or proteins extracted from HIV infected cells. While the University of Washington School of Medicine has recently committed space for the construction of such a facility, equipping and staffing of the P-3 laboratory are needed. This facility is necessary to provide investigators interested in the biochemistry and immunology of HIV proteins access to the reagents essential for their studies. In addition, such a facility would also support viral isolation and neutralizing antibody assays for ongoing and proposed epidemiologic studies. The molecular virology component would be dedicated to recruitment of a senior retrovirologist (using salary support committed by the School of Medicine) with interests complementary to those of the basic molecular retrovirologists at the Fred Hutchinson Cancer Research Center, and to those of the adjacent retrovirology group in the Primate Center.

The second component of the retroviral core is the basic molecular retrovirology program at FHCRC, consisting of several senior scientists working with tumor-associated retroviruses, who have applied for an NIAID Program for Excellence in Basic Research on AIDS (PEBRA) Program Project. To anchor the development of molecular research on HIV at Fred Hutchinson Cancer Research Center, the CFAR and Fred Hutchinson Cancer Research Center will collaborate in renovation and equipping of a laboratory to be dedicated to HIV research at Fred Hutchinson Cancer Research Center, and in recruitment of a retrovirologist who will be fully committed to HIV research. This recruitment will be undertaken jointly with recruitment of the senior retrovirologist for the School of Medicine, and it is anticipated that New Program Development funds will be sought competitively through the CFAR to aid in these joint recruitments.

The third component is the SIV component, consisting of retrovirologists involved in use of the experimental SIV-non human primate model for vaccine development and research on the immunobiology and pathogenesis of SIV infection. A major portion of CFAR funding during the 01 year is requested for alterations and renovations of a third area newly allocated to AIDS-related research in the Department of Microbiology. Retrovirologists at Fred Hutchinson Cancer Research Center and those involved on HIV-related vaccine research will be interacting closely with the SIV research group in this new facility. Thus, the CFAR retrovirology core will be comprised of researchers involved in basic molecular virology, pathogenesis, and clinical retrovirology. The CFAR will promote communication and interactions among these groups, and help to coordinate and support the rapid development of the retrovirology program during the next 3 years.

**KEY PERSONNEL ENGAGED ON PROJECT**

| NAME, DEGREE(S), SSN | POSITION TITLE AND ROLE IN PROJECT | DEPARTMENT AND ORGANIZATION |
|---|---|---|
| Lawrence Corey, M.D.<br>SSN - 363-48-4882 | Director, Retrovirology Core | U.W. Depts. of Laboratory Medicine, Microbiology & Immunology, Medicine, and Pediatrics |
| Maxine Linial, Ph.D.<br>SSN - 133-34-0805 | Associate Director for Molecular Retrovirology, Retrovirology Core | U.W. Depts. of Microbiology & Immunology (Fred Hutchinson Cancer Research Center) |

DESCRIPTION: State the application's broad, long-term objectives and specific aims, making reference to the health relatedness of the project. Describe concisely the experimental design and methods for achieving these goals. Avoid summaries of past accomplishments and the use of the first person. This abstract is meant to serve as a succinct and accurate description of the proposed work when separated from the application. DO NOT EXCEED THE SPACE PROVIDED.

**The Clinical Research Core (CRC) is designed as a centralized facility to improve access to and use of patients with HIV infection for clinical research by affiliated investigators. Toward this end, the CRC will occupy a suite of examination and treatment/procedure rooms and provide a core of staff personnel to accommodate patients referred from the Harborview Medical Center AIDS Clinic (to be relocated adjacent to the CRC) and from other University of Washington clinical services, the Department of Public Health AIDS Prevention Project, the Sexually Transmitted Disease Clinic, private physicians, and other referral sources for participation in clinical research protocols. Location of the cohort study of the natural history of HIV infection in the CRC will provide a population of regularly followed and well characterized HIV-infected and uninfected patients for participation in a variety of studies. For independently funded research projects, the CRC will provide facilities only; for unfunded projects, pilot studies, and clinical research funded through discretionary CFAR funds, CRC staff will be available for clinical examinations, other study procedures, and assistance in data collection and specimen management. Organizationally, the CRC is divided into a General Clinical Research section, primarily for non-therapeutic studies, and the AIDS Clinical Trials Unit (for which no CFAR funds are sought). Beginning in the second year, a Dental/Oral Medicine Module will be formed by fully equipping a room for dental/oral examinations and procedures. Similarly, a fully equipped Ophthalmology Module also will be added in the second year. Gastrointestinal endoscopy capabilities also will be added in the second year and expanded in the third. All CRC patients will contribute to the AIDS registry of the Biostatistics/Epidemiology Core.**

KEY PERSONNEL ENGAGED ON PROJECT

| NAME, DEGREE(S), SSN | POSITION TITLE AND ROLE IN PROJECT | DEPARTMENT AND ORGANIZATION |
|---|---|---|
| H. Hunter Handsfield, M.D.<br>056-34-4400 | Professor<br>Director | Medicine, Epidemiology |
| Ann C. Collier, M.D.<br>218-50-6445 | Assistant Professor<br>Associate Director | Medicine |
| Lawrence Corey, M.D.<br>363-48-4882 | Professor<br>Co-Investigator | Medicine, Laboratory Medicine |

DESCRIPTION: State the application's broad, long-term objectives and specific aims, making reference to the health related [illegible]. Describe concisely the experimental design and methods for achieving these goals. Avoid abstracts of past accomplishments and the of the first person. This abstract is meant to serve as a succinct and accurate description of the proposed work when separated from application. DO NOT EXCEED THE SPACE PROVIDED.

**The Biostatistics/Epidemiology Core will provide collaboration and consulting for the design of CFAR research studies, data collection and management, hardware and software selection and use, and work on needed methodology. The epidemiology of AIDS will be advanced by establishing a registry using state, county and other data sources. The study of the clinical treatment of AIDS will be furthered by establishing a registry of all patients seen in University of Washington affiliated hospitals. Four repositories with an associated registry for the storage of serum, cerebro- spinal fluid, tissue and autopsy specimens will be maintained. The core will maintain an electronic archive of important data sets of the CFAR investigators, which should encourage comparative studies and multiple uses of important data sets. The core will provide computer facilities and expertise for the processing of such data. As individuals involved in the details of many studies, the core will serve to link investigators for collaborative research and to aid communication among the CFAR investigators.**

KEY PERSONNEL ENGAGED ON PROJECT

| NAME, DEGREE(S), SSN | POSITION TITLE AND ROLE IN PROJECT | DEPARTMENT AND ORGANIZATION |
|---|---|---|
| Lloyd D. Fisher, Ph.D.<br>562-50-6538 | Director, Core Program in Biostatistics and Epidemiology | University Of Washington Dept. of Biostatistics |
| Thomas R. Fleming, Ph.D.<br>474-52-4019 | Associate Director Biostatitics | Department of Biostatist |
| Joan Kreiss, M.D., M.S.PH.<br>156-42-5269 | Associate Director, Epidemiology | Department of Epidemiol and Medicine |
| Laura A. Koutsky Ph.D.<br>534-56-4636 | Associate Director, Registries | Department of Epidemiolo |

# XI. Five Year Funding Needs

## Background

The following spectrum of activities should be adequately funded if HIV infection and AIDS are to be prevented and if the service needs of those contracting the disease are to be met in a humane and cost-effective manner.

## AIDS Prevention, Services & Planning Activities

**I. Prevention Activities**

**A. Education**

1. Mass Media (newspaper, radio, TV)
2. Hotlines (includes crisis lines)
3. Speakers Bureau
4. Printed Material (brochures, posters, etc.)
5. Special Events
6. School-based
7. Small Groups/Workshops
8. Outreach
9. Training/Education (for health care professionals and agency staff)
10. Worksite
11. Other

**B. Counseling, Testing and Partner Notification**

1. HIV Counseling ("AIDS counseling" per Omnibus legislation: "directed towards increasing understanding of HIV infection & behavioral change")
2. HIV Testing, Pre- and Posttest Counseling
3. Partner Notification
4. Counseling/Treatment (includes treatment for substance abuse, adding AIDS focus to treatment programs, & in-depth counseling re: high risk behavior resistant to change)

**C. Research**

1. Seroprevalence/Surveillance

**II. Services**

**A. Medical Care (unsponsored)**

1. Primary Care (physician or clinic)
2. Day Treatment
3. Hospital Care (including short stay care)
4. Dental Care
5. Pre-natal/OB Care
6. Mental Health Care

**B. Case Management**

1. Planning
2. Service Delivery

**C. Housing**

1. Residential Long-term Care

    a. Nursing Home Care
    b. Adult Family Home Care
    c. Hospice Inpatient Care

2. Low-Cost Housing

    a. Emergency Housing
    b. Independent Living (includes rent subsidies, subsidized apartments, group homes)
    c. Foster Care

3. Special Populations (includes substance users, mentally ill, pediatric/family)

**D. Community-Based Care**

1. Home Health/Hospice
2. Attendant Care
3. Volunteer Agency Support

    a. Homemaker/Chore, Transportation
    b. Meals/Emergency Food
    c. Emotional Support (one-to-one)
    d. Support Groups & Drop-in Centers
    e. Massage Therapy
    f. Legal Assistance
    g. Information/Referral
    h. Resource Advocacy
    i. Newsletter

4. Professional Counseling
5. Nutrition

    a. Counseling
    b. Food Supplements

6. Day Health (including therapeutic day care)
7. Training/Education (for care-givers)
8. Financial Assistance

**E. Research**

1. Treatment Research
2. Drug Trials
3. Other

**III. Region-Wide Planning and Administration**

# Prevention Funding Needs

**A. Education.** During 1989, assured funding for educational activities in Seattle-King County to prevent the spread of HIV and is $2,350,000. The major funding sources include local (City and County), Robert Wood Johnson Mod Project (RWJ Mod), Centers for Disease (CDC), State Omnibus (Omni 1), Health Resources and Service Administration (HRSA), HRSA Pediatric Grant (HRSA Peds), National Institute for Drug Abuse (NIDA), National Institute for Mental Health (NIMH), Office of Minority Health, and private donors (e.g., Northwest AIDS Foundation Walkathon). Among these, only the NIDA and HRSA Peds grants are assured into 1991.

Through the remainder of 1989, an additional $258,440 is needed, bringing the 1989 total to $2,608,440. Totals needed for future years, by target population group, are shown on the accompanying table. The rationale for these projected needs follows the table.

In reviewing this material, it is important to remember that the target populations overlap. Gay/bisexual men are found among people of color and substance users, for example, as are at risk women. At the same time, the educational approaches and messages aimed at the various target populations will differ, and it is for this reason that the breakdown on the table is given.

# Prevention

| | 1989 Actual | 1989 Addl. Need | 1989 Total | 1990 Needed | 1991 Needed | 1992 Needed | 199 3 Needed |
|---|---|---|---|---|---|---|---|
| Gay/Bisexual[a] | $ 390,747 | $ 39,075[c] | $ 429,822 | $ 494,295[d] | $ 568,440[d] | $ 653,706[d] | $ 751,761[d] |
| Substance Users | 916,483 | 91,648[c] | 1,008,131 | 1,159,351[d] | 1,391,221[e] | 1,669,465[e] | 2,003,358[e] |
| People of Color | 445,572 | 89,114[e] | 534,686 | 641,623[e] | 769,948[e] | 923,937[e] | 1,108,725[e] |
| Out–of–Home Adolescents | 135,721 | 13,572[c] | 149,293 | 171,687[d] | 206,024[e] | 247,229[e] | 296,675[e] |
| In–School Children | 39,127 | 3,913[c] | 43,040 | 49,496[d] | 59,395[d] | 71,274[d] | 85,529[d] |
| Other | 422,350 | 21,118[b] | 443,468 | 443,468 | 443,468 | 443,468 | 443,468 |
| | $2,350,000 | $258,440 | $2,608,440 | $2,959,920 | $3,438,496 | $4,009,079 | $4,689,516 |

[a] In addition to funds allocated for education, substantial funds are allocated each year for counseling and testing which is also a preventive program and much of this is used with gay and bisexual clienta. See later narrative section.

[b] 5% increase

[c] 10% increase

[d] 15% increase

[e] 20% increase

**The rationale for the above recommendations is explained as follows.**

**1. Gay/Bisexual Men.** Additional funds are needed in 1989 for educational efforts to reach a) men who do not self-identify as gay or bisexual, b) youth and c) men who are having a hard time making the behavioral changes necessary to avoid spread of HIV/AIDS. A 10 percent increase is recommended for 1989.

For each year thereafter, a 15 percent increase is projected to be needed to reinforce the prevention messages and to reach new audiences, remembering that the numbers of gay/bisexual males to be reached are greater than the numbers in any other high risk group. **(Note: all funds are shown in 1989 dollars and have not been adjusted for inflation).**

**2. Substance Users.** Though the number of substance users at risk for HIV infection is smaller than that of gay/bisexual men at risk, substance users and their sexual partners as a proportion of all infected is expected to grow dramatically. Education is seen as one of the few weapons which can be used to stem this anticipated development. Furthermore, educating this population is costly, oftentimes requiring one-to-one contact, sometimes repeatedly to effect the necessary behavior change. For these reasons, while there is already $916,500 in committed funds in 1989, another 10 percent is needed this year.

In 1990 another 15 percent increase is needed. This will enable program development in additional neighborhoods in King County and expansion of some programs which are starting to prove themselves (since many programs for substance users are only now being developed and we do not know which will be effective). For years 1991 through 1993, a 20 percent increase each year is projected to be needed.

**3. People of Color.** Reaching people of color who are at risk for HIV/AIDS poses a particular challenge. In some communities there has been considerable denial that AIDS is a problem they need to be concerned about. In addition, among the poor (wherein people of color are over-represented), this is only one message among many being brought to them by outsiders, and when assurance of food and shelter are top priorities, these messages sometimes do not get assimilated. The growing rate of sexually transmitted diseases among some of the ethnic minorities, a rate which is declining in other populations, illustrates the magnitude of the task ahead. A 15 percent increase above assured funds in 1989 should be sought; more could be used but there are constraints created by the amount the primary organizations responsible for these activities can grow.

These organizations should be ready for greater growth in 1990 and beyond, years in which an annual increase of 20 percent is recommended.

**4. Out-Of-Home Adolescents.** This group is at extremely high risk for contracting and spreading HIV infection. Though the group as a whole is small in number, many of them are prostituting themselves and using drugs. They are often more difficult to reach with educational messages than are other at-risk groups because they frequently see themselves as invulnerable. A 10 percent increase over the assured funds is sought in 1989 to expand activities to additional areas of the County.

In 1990 a 15 percent increase in funds is projected to be needed, and in 1991 and beyond, 20 percent per year will be needed.

**5. In-School Children.** In addition to efforts by the Superintendent of Public Instruction to provide AIDS education in the public schools, as mandated by the AIDS Omnibus Act, a small allocation of Seattle-King County AIDS Omnibus funds targeted this population. Further, health educators from the Seattle-King County Department of Public Health are working with the Seattle Public School District.

Still, more is needed since it is during the formative years and with peers that educational efforts can be most effective. Therefore, a 10 percent increase over 1989 assured funds should be sought, and 20 percent each year thereafter.

**6. At-Risk Women with Children.** Women with Children do not constitute a "line item" in the preceeding presentation of funding need because they are found in several other target population groups. In particular, women will be found as partners as IV drug users and among people of color. It is important that attention be given in designing programs for these larger target populations that prevention activities geared toward Women with Children be offered.

**7. Other.** This category includes educational funding targeted toward the General Public, Health Care Professionals, Agency Staff Training, and the Deaf Community. A nominal 5 percent increase over assured funds for 1989 should be found to address additional needs as they are identified. This 1989 level of effort should then be maintained in future years.

**B. Counseling, Testing and Partner Notification.** During 1989, assured funding for these activities is $1,189,975. An additional 30 percent, or $356,993, is needed this year, bringing the 1989 total to $1,546,968. A 30 percent increase each year of the planning period thereafter is also recommended. These amounts would be:

| | |
|---|---|
| 1990 | $2,0ll,058 |
| 1991 | 2,614,375 |
| 1992 | 3,398,688 |
| 1993 | 4,418,294 |

The rationale for this level of increase is that as civil rights assurances are recognized by persons at risk, more will seek testing; as new drugs are found which forstall advances from infection to symptoms, etc., there will be greater interest in early testing; and efforts to accomplish counseling/testing/partner notification with harder-to-reach individuals will cost more. Furthermore, we are only now beginning to understand true demand and cost, and there is some evidence that the earlier 1989 estimates used in allocating current biennium Omnibus funds for these purposes are not adequate.

**C. Research.** During 1989, the research funds coming through the Health Department for seroprevalence and surveillance activities amounted to $626,000. This does not reflect all research dollars coming into the County for the many other activities at the University and within private industry. Because all these need to be weighed before determining the amount the Health Department should seek, and this is done by scientists and academicians and does not require broad-based community input and does not generally compete with the funding for other activities, this plan does not attempt to project the research dollars needed in the County over the next five years.

# Service Funding Needs

Among the spectrum of services which are needed to fully serve persons with HIV infection and AIDS, this funding plan focuses on Case Management, Community-Based Care and a general category called Other. Case Management is included as a focus since it is recognized as the essential ingredient to making this system work, and, since, because of this, we have spent time trying to understand and quantify the magnitude of need in this area over time. Community-Based Care is included because it makes possible non-institutional provision of care which is perceived to more humane and more cost effective. "Other", while a catch-all, is included because it allows us to fill service gaps while programs are being developed, federal waivers applied for, and the like. In this category, for example, we have been able to fund some unsponsored care though we in no way expect the major burden of unsponsored care to be addressed through grants or other funding sources except on an interim basis. (The magnitude of the unsponsored problem should not be underestimated. Non-reimbursed charges for care at the Harborview AIDS clinic alone are expected to amount to several hundreds of thousands of dollars a year by 1991.)

Special mention should be made regarding the needs of HIV infected women and children. They will require case management services and some amount of care which they will not be able to pay for. In seeking and allocating funds, these needs must be addressed.

Another large group which has a need for services is other persons who are HIV positive but who do not have full blown AIDS. Resource constraints have not permitted subsidized services to be available to individuals in this group. Still, as prophylaxis is more successful at keeping infected persons from proceeding to develop AIDS, this group will grow and many will need services. Planning must continue to try to come to grips with this overwhelming resource need. This plan does **not** include these resource needs, but future iterations should when the amount of need is quantified and policies about who can access services are delineated.

It should also be pointed out that this plan does not include the costs of services which are expected to be paid for by public programs which are already in place. Programs such as drug treatment and mental health counseling for the chronically mentally ill are among these. The problem is that these programs have traditionally been underfunded, but it is felt that it is more appropriate to work for adequate funding for these programs through other channels than to add their funding needs to this plan.

The funding requirements for Case Management, Community-Based Care and Other follow with a brief statement of the funding assumptions included on the table. Further rationale for these may be found in the narrative sections of this plan.

## Services

| | 1989 Actual | 1989 Addit. Needed | 1989 Total | 1990 Needed | 1991 Needed | 1992 Needed | 1993 Needed |
|---|---|---|---|---|---|---|---|
| Case Management | $622,758 | $62,276[a] | $685,034[b] | $875,000[b] | $1,200,000[b] | $1,550,000[b] | $2,000,000[b] |
| Community-Based Care | 391,252 | 100,000[c] | 491,252[d] | 741,791[d] | 1,053,343[d] | 1,443,079[d] | 1,868,787[d] |
| Other | 453,931 | 60,000[e] | 503,931 | 692,901[f] | 965,718[f] | 1,282,748[f] | 1,631,213[f] |
| | $1,467,941 | $222,276 | $1,680,217 | $2,309,701 | $3,219,061 | $4,275,827 | $5,500,000 |

[a]10% Increase

[b]In 1989, basic case management accounted for 60% of allocations while 40% was for case management for special populations of PWAs, including Infants/Children/Families and Mentally Ill. These proportions were maintained in calculating future years. "Basic case management" requirements were figured by multiplying projected numbers of surviving PWAs in that year by 75% (as the numbers needing case management) and dividing by 45 (for caseload) and multiplying by $38,500 average salary plus fringe.

[c]$100,000 is approximately 1/2 of additional needs identified by agencies/organizations during summer '88 Omnibus Planning. Assumes some overlap in these applications andthkat some economies could be realized if funds actually available.

[d]Increases proportionate to % increases of numbers of surviving PWAs from kyear to year.

[e]Assumes there is limited additional need from major public and private funding sources.

[f]Assumes need for "Other" in future years is in proportion to 1989 "Other" vs. total service need.

## Region-wide Planning And Administration

In 1989, $819,346 of assured funding is allocated for these purposes. If we assume that the need in this area would remain in direct proportion to all funding needs as it is currently with respect to assured funds, these amounts needed for Planning and Administration would be these:

| | |
|---|---|
| 1989 | $ 951,613 |
| 1990 | $1,185,227 |
| 1991 | $1,509,384 |
| 1992 | $1,901,980 |
| 1993 | $2,378,015 |

## Total Funding Needs by Year

To summarize, all funding needed for AIDS Prevention, Services and Planning/Administration in Seattle-King County over the next five years is as follows.

| | 1989 | 1990 | 1991 | 1992 | 1993 |
|---|---|---|---|---|---|
| Education | $2,608,440 | $2,959,920 | $3,438,496 | $4,009,079 | $4,689,516 |
| C/T/P Not | 1,546,968 | 2,011,058 | 2,614,375 | 3,398,688 | 4,418,294 |
| Services | 1,690,217 | 2,309,701 | 3,219,061 | 4,275,827 | 5,500,000 |
| Plan/Admin | 951,613 | 1,185,227 | 1,509,384 | 1,901,980 | 2,378,015 |
| Total* | $6,797,238 | $8,465,906 | $10,781,316 | $13,585,574 | $16,985,825 |

*Grand total needed $56,615,859

Assured funding in 1989 amounts to $6,453,362; in 1990 it is $4,531,032; and in 1991, it is $1,776,043. There is no assured funding beyond 1991. After backing out the total assured funds of $12,760,437, there remains a need for $43,855,422 to address the AIDS epidemic in Seattle-King County over the next five years.